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A MATTER OF CHOICE: PLANNING AHEAD FOR HEALTH CARE DECISIONS

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PREFACE

Tremendous advances in health care technology and unprecedented growth in the number of Americans living to old age continue to create profound new challenges for our society. Improvements in medical care technology are a tribute to this Nation's commitment to research and innovation. These same technologies, however, can threaten to erode cherished American values of autonomy and freedom of choice. Older Americans are especially at risk as serious illness and incapacity often decrease their ability to make and communicate choices about health care. The challenge we face as a Nation, therefore, is to protect the rights of individuals while pursuing the best medical care possible.

To meet this challenge, State legislative bodies, in conjunction with legal and medical professionals and advocates for the elderly and disabled, have devised mechanisms for Americans to express their wishes and make choices in advance about future health care needs. Among these advance directives are so-called "living wills" and durable powers of attorney. While these may not be the only possible vehicles for exercising choice, their widespread availability and use make them a subject of great interest to those who work with the aged.

While this paper addresses an important issue in our society, we recognize that there are other significant and highly sensitive issues involving health care and technology. We view this paper as the first of a two-part series concerning health care technology. We anticipate that the Special Committee on Aging will issue a follow-up paper that examines the complex and often highly charged issues of allocation of health care resources and the potential for discrimination against and abuse of the elderly and the disabled in health care decisionmaking and treatment. It is our view that discussion of advance directives for health care decisionmaking would be complemented by a second paper that critically analyzes these issues from differing, and often competing, perspectives.

For now, we are pleased, to make this report available to those who counsel, advise, and represent older persons. Lawyers, physicians, and other health care professionals, clergy, social workers, and others are in key positions to ensure that the difficult decisions made on behalf of others preserve personal values, preferences, and dignity. More directly, we hope that this report will help individuals understand the options available to them as they plan ahead to protect their fundamental right of personal autonomy in health care decisionmaking.

This paper reflects the views of the author and does not necessarily reflect the views of any individual committee member.

JOHN HEINZ,
Chairman.
JOHN GLENN,
Ranking Member.

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Special thanks are also due to several individuals who contributed to the writing and production of this document, including William Benson and Susan Beecher, staff of the Special Committee on Aging, and William Amatruda and Jeff Stryker, who provided valuable research assistance.

Finally, Senator Heinz and Senator Glenn wish to especially recognize the enormous contribution made by the advisory committee formed to review and critique this document. A list of advisory committee members follows.

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INTRODUCTION

Communication is essential to health care decisionmaking. In order to make a decision about health care, a patient must be able to understand the available treatment options and appreciate the implications of choosing one option rather than another. The patient also must be able to make a choice and to communicate that choice. If any of these elements are lacking, the decision will be made by someone else.

When patients are unable to make decisions because of physical or mental incapacity at the time a treatment choice is presented, communication in advance is the most reliable way of assuring that the individual's preferences and values are considered by those who must make the decisions.

Family members, caregivers, judges and legal representatives are the ones who traditionally are called upon to make health care decisions on behalf of incapacitated adults. If there has been no prior communication with the patient, these decisionmakers will find it difficult to know what choices the patient would make under a given set of circumstances. Worse, they may disagree among themselves as to what the patient would prefer.

This report describes some of the problems that can arise in the absence of good communication among patients, family members, and caregivers. It also describes two kinds of written directives that can minimize the difficulties by stating in advance how choices about health care should be made if certain circumstances should develop in the future, and explains legal devices for making anatomical gifts. The first kind of directive provides specific instructions about the kinds of health care that should be provided or foregone in particular situations. The second kind appoints an agent to make health care decisions in the event of the appointing individual's subsequent incapacity. The appointment directive can be combined with specific instructions thus giving the agent not only legal authority to act in certain situations but also instructions as to how to act.

Advance directives for health care extend an individual's self-determination to circumstances in which self-expression is no longer possible. By doing so, they alleviate some of the burden on family members and caregivers who must make difficult choices on behalf of a patient who is unable to make or communicate decisions about medical treatment.

Equally important, however, are the opportunities and incentives that advance directives provide for discussion among family members and caregivers in advance of a medical crisis. Discussion is important because pivotal terms typically used in advance directives (such as terminal illness, imminent death, supportive care, and competence or capacity to make decisions) often are not well defined in the law. Sometimes they are left undefined, and sometimes

the legal meaning differs from either the medical or the common understanding of the term.

The purpose of this report is to facilitate the use of advance directives and to encourage communication between those who write them and those who must carry them out. The report is written for policymakers, health care professionals, attorneys, social workers, members of the clergy, and others who counsel patients and their families or who advocate on behalf of the elderly. It may also be useful for people who are currently in good health but who wish to make arrangements for their future care as part of the important process of preparing for possible physical or mental disability.

Chapter I explains why it is important to know how to plan ahead for decisions about health care and the problems that can arise in the absence of advance planning. Chapter II describes traditional approaches to health care decisionmaking, such as the informed consent of the patient, family consent, and court proceedings for guardianship or conservatorship.

Chapter III describes more recent approaches, known as advance directives, and explains the advantages and disadvantages of "living wills" and durable powers of attorney. It also discusses anatomical gifts and provides basic information about Federal and State laws.

Chapters IV (Bibliography) and V (Resources) are designed to assist the reader in obtaining additional information through further reading or by contacting one of the organizations listed. Chapter VI is a checklist for advisors.

I. THE IMPORTANCE OF MAKING CHOICES ABOUT PERSONAL HEALTH CARE

Mary Severns, age 55, broke her neck and suffered extensive brain damage in an automobile accident. She was comatose when taken to the hospital immediately following the accident and remained in a coma thereafter, although she regained sufficient function to breathe without a respirator. She was fed through a naso-gastric tube and it was virtually certain that she would never emerge from her coma, described by doctors as a "persistent vegetative state."

A year following the accident, her husband asked that she not be put back on the respirator and that no drugs or medicines be administered except those necessary to maintain personal comfort and hygiene. When the attending physician refused to enter such an order, Mr. Severns petitioned the court to appoint him guardian and to authorize him to request that life-supporting treatments be withheld or withdrawn. He also asked the court to protect the physicians and the hospital from criminal or civil liability if they would comply with his request.

The Court of Chancery, uncertain as to its powers, referred the matter to the Delaware Supreme Court, which held that Mary Severns had a constitutional right to refuse treatment and that her husband, as guardian, could exercise that right on her behalf. "[T]o deny the exercise [of the right] because the patient is unconscious would be to deny the right." [1] *The case went back to the Court of Chancery which ultimately granted all of Mr. Severns' requests.* [2]

Mary Severns had been a member of an association advocating death with dignity and, five years before her accident, had suggested to her husband that they each sign a living will. She wanted to document her wish that "in the event she were to become unable to reason and care for herself as a result of an accident or illness . . . she did not want to be kept alive in a vegetative state but would like to be allowed to die with dignity." [3] *She never executed a living will, however, apparently because of her husband's reluctance to do so.* [4]

A. Making Choices About Personal Health Care Is a Fundamental Right

In the United States, we cherish—and vigorously protect—our fundamental rights. One of the most basic is the right to privacy, which has been interpreted by many courts as including the right

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[1] *Severns* v. *Wilmington Medical Center*, 421 A.2d 1334, (1347, Del. 1980).
[2] In *re Severns*, 425 A.2d 156 (Del. Ch. 1980).
[3] Id. at 158.
[4] Id.

to make one's own health care decisions and, by extension, to have those decisions implemented by others, if necessary.[5]

Over seventy years ago, Judge Cardozo (then recently appointed to New York's highest court) stated the basic principle underlying consent to health care:

> Every human being of adult years and sound mind has a right to determine what shall be done with his own body and cannot be subjected to medical treatment without his consent.[6]

Several years later, Supreme Court Justice Brandeis elaborated the concept of personal privacy, setting forth the principle that has since formed the basis of many court decisions about the right to refuse treatment:

> The makers of our Constitution . . . sought to protect Americans in their beliefs, their thoughts, their emotions and their sensations. They conferred, as against the Government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized men.[7]

The right to privacy—the right to be let alone—is particularly important in health care. With few exceptions, every adult who is capable of doing so has the right to decide which treatment to accept, and which to refuse.

Occasionally, society may limit the right to make decisions about health care, usually to protect the public health (for example, by requiring a person to be vaccinated or quarantined). In rare instances, courts have required adults to accept unwanted treatment to protect the health and welfare of an unborn child or of dependent children, but that has happened in the vast majority of cases only when the treatment in question would restore the patient to a normal, healthy life. Such cases are very different from situations in which individuals may wish to refuse treatment that will mainly prolong a life of multiple incapacities and discomfort, and that will serve only to forestall—however briefly—impending death.

B. Maintaining Control Over Personal Health Care Is Important for Dignity and Well-Being

A frequent complaint both of hospital patients and of the elderly is that they are treated with little respect—or worse, as if they have ceased to exist. When physical and mental infirmities force dependence upon others, it is difficult to maintain independence of thought and personal dignity.

Scientific studies of emotional responses to stress strongly suggest that loss of the ability (or perceived ability) to control events can lead to both physical and emotional illness.[8] Thus, it is impor-

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[5] *See, e.g., Tune* v. *Walter Reed Army Medical Center*, 602 F. Supp 1452 (D.D.C. 1985); *Bartling* v. *Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 220 (1984); *John F. Kennedy Memorial Hospital* v. *Bludworth*, 452 So. 2d 921 (Fla. 1984); and cases cited therein.

[6] *Schloendorff v. New York Hospital*, 211 N.Y. 125, 105 N.E. 92, 93 (1914).

[7] *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (dissenting opinion). Although all of the courts that have ruled on health care decisions have recognized a right to privacy, some have based their rulings on state constitutions or on a common law right to privacy rather than on a right emanating from the United States Constitution.

[8] J. Rodin, "Aging and Health: Effects on the Sense of Control," *Science*, Vol 233, No. 4770, 1271-1276 (Sept. 19, 1986).

tant to both physical and emotional health that individuals maintain control over their lives, particularly their medical care, to the extent they are able to do so and especially if they are already experiencing the stress of illness or physical incapacity.

Decisions that must be made about the health care of incapacitated individuals may include not only whether to withhold or withdraw life-support systems, but also whether to place the patient in a nursing home or a hospice, whether to perform invasive diagnostic tests (to determine, for example, if the patient has cancer), whether to perform dental surgery, and whether to insert a feeding tube. Usually, when a patient is incapacitated, such decisions are made by next of kin, in consultation with the patient's physicians. However, if there are disagreements among the family members or physicians, or if the family's decision differs from a medical consensus regarding proper treatment, the health care facility may insist that the decision be made only by an individual—or a court—having clear legal authority to give (or withhold) consent on behalf of the patient.

C. Few People Have Planned Ahead for Health Care Decisions

Despite the importance of maintaining control over one's health care, few people have made arrangements for someone to carry out their wishes in case they become unable to give directions concerning their own care. In 1982, a survey conducted by Louis Harris and Associates revealed that only about one-third of the general population had given instructions to someone concerning how they would like to be treated in the event they are unable to make their own decisions about health care; and of those, only about one-fourth had put their instructions in writing.[9]

In the same survey, physicians were asked how they would treat a patient in the end stage of a painful and terminal illness, if the patient were unable to communicate his or her wishes. If the patient had left written instructions not to prolong life through extraordinary means, most of the physicians said they would not resuscitate in the event of cardiac or respiratory arrest.

Later studies strongly suggest that physicians often do not have a good understanding of their patients' wishes concerning resuscitation and, although the physicians say that such matters should be discussed with their patients, they actually do so infrequently.[10]

D. Providers of Health Care, Attorneys, and Others Are Sometimes Unsure as to What Is Required

Occasionally, people who have prepared written instructions about their health care report that physicians and hospital personnel were unsure as to what to do with them. In the absence of clear policies and procedures for asking about such documents and making them a part of a patient's medical record, health care per-

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[9] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions*, Vol. 2, Appendix B (1982).

[10] S. Bedell and T. Delbanco, "Choices About Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk With Patients?", *New Eng. J. Med.*, Vol. 310, No. 17 (April 26, 1984) at 1089.

sonnel may not know about—or implement—the few that have been prepared.

More attorneys need to be educated. Some of those who prepare wills and similar documents for the control and disposition of property after death do not fully appreciate the importance of encouraging their clients also to prepare for the care and disposition of their person during illness. Yet, similar principles apply.

Preparation of advance directives helps to assure that the individual's wishes about health care will be carried out. Written instructions also will relieve family members of much of the burden of making difficult decisions at a time when they may be under considerable stress, and can dispel confusion and conflict among close relatives who may have differing views as to what the patient would want. Attorneys should explain the nature and scope of the right to make choices about health care to all clients who request advice concerning estate planning and assist those who would like to prepare advance directives for health care at the same time that they prepare wills and trust agreements.

Nurses, social workers, physicians, clergy, and others who counsel individuals and their families could provide much more assistance if they were better informed about procedures for making advance directives concerning health care.

II. LEGAL PROTECTION OF PATIENTS' RIGHTS: TRADITIONAL APPROACHES

Bertha Harris was 73-years-old, and suffering from diabetes and circulatory problems, when she was transferred from a nursing home to a hospital for surgery. She understood that the gangrene in her foot would probably spread, and she consented to amputation of her left leg, above the knee. Both her sister and niece (who was a court-appointed conservator of Ms. Harris' estate) also consented to the operation.

Two weeks later, the physicians found a small, black patch on the bottom of her right foot and recommended that the right leg also be amputated above the knee. Bertha Harris refused. When the physicians could not persuade Ms. Harris—or her sister or niece—to consent to the second amputation, the hospital petitioned the court to declare her incompetent and to authorize performance of the amputation against her will.

The District of Columbia Court of Appeals preserved Bertha Harris' right leg—and her individual rights—by sending the case back to the trial court with directions that a judicial determination of incompetency would require clear and convincing evidence that Bertha Harris lacked the specific capacity to make the health care decision.[11] *The appellate court also ruled that Bertha Harris had the right to be examined by a psychiatrist and a physician of her own choosing.*

Following further evidentiary hearings, the trial court found that Bertha Harris "understands the nature and consequences of the treatment choice being presented with respect to amputation of her leg, and chooses not to have the amputation at this time."[12] *The Court therefore ruled that:*

> *Although there is convincing evidence, which the Court accepts, that the patient suffers confusion and lapse of memory, the [hospital] has not established a particularized connection between those conditions and the ability of the patient to make a treatment decision respecting her leg. See Lane v. Candura, 376 N.E. 2d 1232, 1235 (Mass. App. 1978). Absent the requisite showing of a particularized lack of competence to make a decision respecting amputation of her leg, the patient has a right to decline treatment, and there is no basis at this time on which the Court may or should interfere with her exercise of that right.*[13]

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[11] *In re Harris*, 477 A.2d 724 (D.C. 1984).

[12] *In the Matter of Bertha Harris*, Misc. No. 126-84 (D.C Super. Ct., June 4, 1984) (slip op. at 2).

[13] *Id.* at 2-3.

Families and physicians confronting the need to make decisions about the health care of an incapacitated adult traditionally have taken one of three approaches: (a) the physician has made the decision (usually—but not always—after discussing it with family members); (b) family members have made the decision, in consultation with the physician; and (c) family members or the health care facility have petititoned for court appointment of a guardian or conservator—or for a judicial answer to the question posed.

The case of Bertha Harris illustrates traditional methods of resolving decisions about the health care of individuals whose competence to decide is in question. The hospital obtained the consent of available family members, in addition to consent of the patient, for the first amputation.[14] When all three refused permission to amputate the second leg, the hospital petitioned the court to determine, as a matter of law, whether the patient was competent to make a decision regarding the proposed surgery. The hospital also asked the court to authorize the surgery if it concluded that Ms. Harris lacked the competence to make her own decision regarding the second amputation. Several important principles, illustrated by this case, are discussed below.

A. Consent by the Patient (or a Legally Authorized Representative) Is Required

1. COMPETENT PATIENTS

A physician or other health care provider may not administer treatments, diagnostic tests, or surgical interventions without the consent of the patient. If medical interventions are administered without consent, the doctor (and health care facility) may be sued for battery or for negligence.[15] Of course, if an emergency exists and an advance directive to the contrary is not immediately available, physicians may administer care necessary to preserve life and limb without consent of the patient or a legal representative. (Under the theory of implied consent, the law permits them to assume that the patient *would* consent to emergency treatment, if the patient were able to make the decision.)

In the absence of an emergency, physicians may not presume to make decisions for their patients. Competent, adult patients have the right to make their own decisions, even if those decisions are not the ones their physicians would make for themselves, and even if their decisions seem unwise or foolish to others. Former Chief Justice Warren Burger once wrote that when our founding fathers sought to protect the right to make one's own decisions, they intended to protect even "a great many foolish, unreasonable and even absurd ideas which do not conform, such as refusing medical treatment even at great risk." [16]

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[14] *In the Matter of Bertha Harris*, Misc. No. 126-84 (Super. Ct. D.C.), transcript of hearing on June 1, 1984, at 35-36.

[15] *See generally* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions*, Chapter 1 (1982). See also Leach v. Shapiro, 469 N.E.2d 1047 (Ohio, 1984).

[16] *Application of President and Directors of Georgetown College*, 331 F.2d 1000, 1017 (1963) (Burger, J., dissenting from denial of rehearing *en banc*).

The last point is important, because it makes clear that a patient not be deemed incompetent on the basis of what appears to be a foolish or irrational decision. Bertha Harris' physicians did not question her competence when she consented to the first amputation. It was only when she refused to consent to the second that her competence was called into question.[17] Thus, the only behavioral change leading to the change in status was her refusal to accept an operation that her physicians strongly recommended. As the court made clear, however, Bertha Harris had the right to make a decision contrary to the one her doctors thought she should make, so long as she understood the nature and the consequences of that decision, as explained more fully below.

In protecting the right of patients to make their own choices, the law enforces widely accepted ethical principles concerning individual autonomy, also referred to as self-determination. That principle states that individuals have the right to self-determination so long as their exercise of that right does not infringe the rights of others. It is a principle that underlies many of the individual freedoms protected by our Constitution. Physicians, of course, also have rights; and when a patient's exercise of self-determination results in a decision that conflicts with a physician's personal beliefs or values, the physician is not obligated to comply. Instead, it is generally expected that the physician will transfer the patient's care to another physician whose beliefs or values are more compatible with the patient's.

2. DETERMINING A PATIENT'S COMPETENCE OR CAPACITY TO CONSENT

An adult is presumed to be competent unless a court has made a determination to the contrary. Even after an adjudication of incompetency, however, an individual may have the capacity to make decisions about health care.

The terms "competency" and "capacity to consent" are often used interchangeably. However, "competency" is technically a legal term, generally referring to a court determination. By contrast, "capacity to consent" or "decision-making capacity" describes an individual's ability to make a health care decision. Only a few state statutes governing consent to health care have defined capacity to consent. For example, individuals who may consent to health care in Idaho are defined as:

> Any person of ordinary intelligence and awareness sufficient for him or her generally to comprehend the need for, the nature of and the significant risks ordinarily inherent in any contemplated hospital, medical, dental or surgical care, treatment or procedure. . . .[18]

Similarly, in Mississippi, persons who are of "unsound mind" and therefore unable to consent to health care are defined as those who are:

> unable to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures

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[17] A similar sequence of events occurred in a Massachusetts case, *Lane* v. *Candura*, 376 N.E.2d 1232 (Mass. App. 1978).

[18] Idaho Code, Chap. 43, § 39-4302 (Michie 1985).

> so as to intelligently determine whether or not to consent to the same, regardless of whether such state of mind is only temporary or has existed for an extended period of time or occurs or has occurred only intermittently and whether or not it is due to natural state, age, shock or anxiety, illness, injury, drugs or sedation, intoxication or other cause of whatever nature.[19]

By contrast, in Maine, a valid consent to health care is defined merely as "one which is given by a person who, under all the surrounding circumstances, is mentally and physically competent to give consent." [20] Maine's statutory definition, although circuitous, is nevertheless an attempt to provide guidance. A majority of states leave the term undefined.

A determination concerning an individual's decisionmaking capacity must be made with reference to a specific treatment choice and at a particular time. The determination is usually made by the patient's attending physician, sometimes in consultation with a psychiatrist, clinical psychologist, or neurologist.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter referred to as the President's Commission) analyzed the legal and ethical issues surrounding decisional incapacity in its 1982 report on *Making Health Care Decisions.*[21] The Commission endorsed the traditional method by which a patient's decisionmaking capacity is determined by the attending physician, in consultation with relatives, close friends, and other caregivers.[22] Recourse to the courts, according to the Commission, should be necessary only when uncertainty or conflict about the patient's decisionmaking capacity cannot be resolved at the institutional level.[23] The capacity for health care decisionmaking is generally understood to depend upon the ability to:

1. Understand the nature of the treatment choice presented;
2. Appreciate the implications of the various alternatives; and
3. Make and communicate a reasoned choice.

In determining whether a patient understands the implications of the choices presented, it is useful to assess the extent to which the choice made by the patient is consistent with what is known of the patient's personal goals, religious beliefs, and values. Relatives, friends, and those who have provided spirtual or personal counsel to the patient in the past can often provide important information about such matters.

Special considerations apply in determining the decisionmaking capacity of patients with cognitive impairments. Their recent memory as well as their thought processes may be compromised. In addition, they may be depressed or angry (or both) because of infir-

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[19] Miss. Code Ann. § 41-41-3 (Supp. 1985).
[20] Me. Rev. Stat. Ann. tit. 24 § 2905(3) Supp. (1985).
[21] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (1982), Chaps. 8 and 9, at 167-188.
[22] Id. at 172-173.
[23] Id. at 175.

mities that limit their independence and deprive them of dignity.[24] Therefore, it is important that practitioners assessing a patient's decision-making ability have appropriate skills and experience in, for example, geriatric psychiatry, neurology, or clinical neuropsychology. Finally, patients in a health care facility may be attended by medical personnel who come from different cultures, have different values, and may not be fluent—or understandable—in spoken English. This should be taken into account in evaluating assessments of a patient's responses made by such personnel.

Consider again the case of Bertha Harris. She performed poorly on a mental status exam, routinely used to determined competency, that depends heavily on the ability to remember lists of words and numbers and to count backward from 100 by sevens. She also had trouble responding to the questions put to her by a foreign-born psychiatrist whose spoken English was very difficult to understand. As a result, the psychiatrist testified that Bertha Harris was incompetent because she "had difficulty grasping" what was said to her.[25] Nevertheless, she repeatedly demonstrated that she understood that the doctors wanted to amputate her second leg; she understood that they thought she would die within weeks if the surgery were not performed, and she clearly stated that she would rather die than go to her grave without the leg.[26]

Bertha Harris also persisted in claiming that she was 37, although she knew the correct date of her birth. The hospital psychiatrist interpreted this as another sign of incompetence. However, under sensitive questioning by another physician, Bertha Harris stated that she could not be 73 (her true age) because "that would be old"; and when asked what was wrong with being old, she replied: "people don't care about old people." [27] As the consulting physician later observed, the misstatements about her age may have revealed more about Bertha Harris' fears than about any memory deficit.[28]

B. State Family Consent Laws

If the attending physician determines that a patient lacks the capacity to make a health care decision (and if everyone concerned agrees that is the case), who may make the decision on the patient's behalf? The answer depends upon state law or, in the case of facilities operated by the Federal Government, upon the laws and regulations of the department or agency in charge.

By September 1986, a dozen states had enacted statutes providing clear legal authority for family members to make health care

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[24] Recent studies by the National Institute of Mental Health found mild cognitive impairment in about 14% of persons age 65 and older, and severe impairment in 5.6% of the men and 3% of the women in that age group. A 1977 survey of nursing homes, conducted by the National Center for Health Statistics, found that one-fifth of nursing home residents had a primary diagnosis of mental disorder or senility without psychosis. *Aging America: Trends and Projections*, prepared by the Senate Special Committee on Aging in conjunction with the American Association of Retired Persons, the Federal Council on Aging, and the Administration on Aging (1985-86 Edition) at 91.

[25] *In the Matter of Bertha Harris*, Misc. No. 126-84 (Super. Ct. D.C.), transcript of hearing on May 25, 1984, at 48, 51, 56, 57.

[26] *Id.*, at 13, 15, 23, 35; *see also id.*, transcript of hearing on May 30, 1984, at 30-31; and *id.*, transcript of hearing on June 1, 1984, at 48-56.

[27] *Id.*, Testimony of D. Joanne Lynn, M.D., Transcript of Hearing on May 31, 1984 at 12-13.

[28] D. Joanne Lynn, M.D. (Personal Communication).

decisions on behalf of an incapacitated adult, under certain circumstances. In six of those states, a family member may make all health care decisions for an incapacitated patient (except, in Maryland, for sterilization, abortion, and treatment or hospitalization for a mental disorder). Nine additional states had passed laws giving family members authority to make decisions for an incapacitated patient if a physician certifies that the patient is terminally ill. (See Table 1.) In at least six states, court decisions have validated the right of family members to make health care decisions, including withholding or withdrawing life prolonging treatment, for terminally ill or comatose patients.[29]

TABLE 1.—FAMILY CONSENT STATUTES

State	Statute
Family may make health care decisions for incapacitated adults:	
Arkansas	Ark. Stat. § 82-363 (1976).
Georgia	Ga. Code § 31-9-1 (1982).
Idaho	Idaho Code § 39-4303 (1985).
Louisiana	La. Rev. Stat. Ann. tit. 40, § 1299.53 (1977).
Maine	Me. Rev. Stat. Ann. tit. 24, § 2005 (1985).
Maryland [1]	Md. Ann. Code § 20-107(d) (1984).
Mississippi	Miss. Code Ann. § 41-41-3 (1985).
Utah	Utah Code Ann. § 78-14-5(4) (1977).
Family may make health care decisions for terminally ill and incapacitated adults (including termination of treatment):	
Florida	Fla. Stat. Ch. 84-85, § 765.0 (1984).
Iowa	Iowa Code Ch. 144A.1-144A.12 (1985).
Louisiana	La. Rev. Stat. tit. 40, § 1299-58.5(A) (H.B. 795, 1985).
New Mexico	N.M. Stat. Ann. § 24-7-5, as amended by S.B. 15 (1984).
North Carolina [2]	N.C. Gen. Stat. § 90-322(b), as amended by S.B. 240 (1983).
Oregon [2]	Ore. Rev. Stat. § 97-083(2), as amended by H.B. 2963 (1983).
Texas	Tex. Civ. Stat. Art. 4590h, as amended by H.B. 403 (1985).
Virginia	Va. Code Ann. § 54-325.8:6 (1984).
Utah	Utah Code Ann. §§ 75-2-1101-1118 (1985).

[1] Except for sterilization, abortion, and treatment or hospitalization for a mental disorder.
[2] Patient must be comatose.

In states having no family consent law, hospitals and physicians may either choose to rely on family consent or petition a court for appointment of a guardian or for judicial authorization of treatment.

A Model Health Care Consent Act was recently adopted by The National Conference of Commissioners of Uniform State Laws, a body of judges and legal scholars who develop model legislation that they recommend for adoption by the individual states.[30] Section 4 of the Model Act provides that, when a patient is incapable of providing consent and has not designated another to make health care decisions, such decisions may be made on the patient's behalf by a spouse, adult child, parent, or adult sibling. (If a guardian or legal representative has been appointed in a judicial proceeding, that person would have priority over the family members.) Under Section 3 of the Model Act, an adult is presumed capable of

[29] Case law in California, Connecticut, Florida, Georgia, New Jersey, and Virginia supports the right of family members to make health care decisions—including decisions to forego treatment—for terminally ill or comatose patients.
[30] Uniform Law Commissioners' Model Health-Care Consent Act, 9 U.L.A. 332 (West Supp. 1984), reprinted as Appendix F of this report.

consenting and thus, may consent "unless, in the good faith opinion of the health-care provider, the individual is incapable of making a decision regarding the proposed care."

The model act gives equal priority to all family members and provides no guidance on how to proceed if family members disagree. By contrast, some states specify the priority in which family members are authorized to act, and others require unanimity of all members in a given category (*e.g.*, adult children). (See Table 2.) The model act emphasizes that individuals making health care decisions for incapacitated patients should be guided by the patient's previously expressed preferences and values, to the extent they are known—or can be determined.

Although the model act was approved by the Uniform Law Commissioners in 1982, it has had little impact to date. As the Commissioners observed in a footnote to their introductory remarks: "There is no reason to believe that those states that enacted informed consent legislation [within the last decade] are dissatisfied with their efforts nor is there reason to believe that uniform legislation on this subject would be enacted by those states that decided not to adopt informed consent legislation in the 1970's." [31]

[31] 9 U.L.A. at 332 (West Supp. 1984), n.1.

TABLE 2.—PROVISIONS OF FAMILY CONSENT LAWS

State	Patient must be—		Family members—					Priority given	Consent not valid for—		
	Terminally ill	Comatose	Spouse	Adult child	Parent	Adult sibling	Other		Abortion	Sterilization	Mental health care
Arkansas			X	X	X	Nearest relative	Grandparent				
Florida	X		X	[2]X	X		Nearest relative	X			
Georgia			X		[1]X	[1]X	Grandparent	X	X		
Idaho			X		X		Any competent relative				
Iowa	X		X	[2]X	X	X					
Louisiana			X		[1]X	[1]X	Grandparent [1]		X	X	X
Louisiana *	X		X	[2]X	[2]X	[2]X	Other ascendents or decendents [2]				
Maine			X		X		Nearest relative				
Maryland			X	X	X	X	Grandparent; adult grandchild	X	X	X	X
Mississippi			X	X	X	X	Grandparent				
New Mexico	X	or X	X	X	X	X	Family members [4]	X			
North Carolina	X	and X	X	X	X	X		X			
Oregon	X	and X	X	[2]X	X	X					
Texas	X		X	[2]X	X		Nearest relative	[3]X			
Utah			X	X	[1]X	[1]X	Grandparent [1]				
Virginia	X		X	X	X		Nearest relative	X			

*Louisiana has two family consent laws.
[1] For minor child.
[2] Majority of this class required (if available).
[3] Requires consent of at least two family members, if reasonably available.
[4] All who can be contacted must agree on what patient would choose.

C. Federal Law

1. REGULATIONS

Consent to health care, the right to refuse treatment, and family consent are typically governed by state law. However, federal facilities (such as Veterans Administration hospitals, military hospitals, and health care facilities operated by the Public Health Service) are not required to follow state law. Instead, the rights of patients in federal facilities are governed by the regulations and policies of the agency operating the facility.

In November 1985, Senators Heinz and Glenn, Chairman and ranking member of the Senate Special Committee on Aging, wrote to the heads of federal agencies that operate health care facilities requesting information about their regulations and policies concerning consent to health care and the right to refuse treatment. Responses were received from the following:

Department of Defense:
—*Department of the Air Force:* Michael C. Kerby, Brigadier General, Deputy Director, Legislative Liaison.
—*Department of the Army:* Delbert L. Spurlock, Assistant Secretary of the Army (Manpower and Reserve Affairs).
—*Department of the Navy:* James F. Goodrich, Acting Secretary of the Navy.
Department of Health and Human Services:
—*Public Health Service:* Donald I. Macdonald, M.D., Acting Assistant Secretary for Health, on behalf of:
—*Indian Health Service*
—*Gillis W. Long Hansen's Disease Center*
—*National Institutes of Health:* James B. Wyngaarden, M.D., Director
Federal Bureau of Prisons: Norman A. Carlson, Director
Veterans Administration: Everett Alvarez, Jr., Acting Administrator

The descriptions below are based upon letters received from agency officials and supporting documentation that was attached.[32]

Department of Defense

The Department of Defense has no department-wide policy governing health care decision-making. Instead, the Air Force, Army, and Navy develop and implement their own policies, as described below.

Air Force

Although there is no requirement that it do so, the Air Force follows the laws of the state in which its medical facilities are located. As a result, terminally ill patients may refuse life-sustaining treatment to the extent consistent with the law and medical practice of the host state. If medical personnel determine that a patient lacks the capacity to make a decision regarding health care, family consent is accepted according to the state law. In medical facilities out-

[32] Copies of all documents received are available from the Senate Special Committee on Aging.

side the United States, decisions are made "in accordance with United States Law." [33] In the case of active duty personnel, a treatment refusal is reviewed by an evaluation board to determine whether the decision not to submit to recommended treatment will interfere with the patient's physical qualifications for active military service.[34]

Army

The Army expressly follows the general policies of the President's Commission regarding the right of patients to refuse treatment.[35] Any competent patient may direct that life-sustaining procedures be withheld or withdrawn after discussion with the attending physician. Medical personnel are directed to proceed according to the patient's wishes. If a clinical assessment of the patient's mental and emotional status reveals incapacity to make a health care decision, family members may make decisions on behalf of the patient, according to the law of the state or jurisdiction in which the medical facility is located. Life-sustaining procedures may be withdrawn from an incapacitated patient who is terminally ill or in a chronic or persistent vegetative state with the consent of next of kin or legal guardian and the concurrence of the attending physician. If there are differences of opinion among those parties, advice and consultation may be obtained from an ethics committee.

Navy

In the absense of evidence to the contrary, the Navy presumes that its patients are competent, in which case they have sole authority to consent to or refuse medical treatment.[36] If an adult patient is determined to be either incompetent or of diminished competence, treatment decisions may be made by the person authorized under state law to consent on his or her behalf.[37] Orders not to resuscitate a patient ("DNR" orders) may be written by the attending physician only after consultation with the patient, or if the patient is incapable of making a decision, with the patient's family. If there are disagreements among the patient, family members, and physician concerning DNR orders (or similar decisions concerning terminally ill patients), or if the lives of others are implicated, the case must be reviewed by the facility's ethics committee.[38] Discussions with the patient and family must be witnessed by a registered nurse, social worker, or higher authority; and determinations of decision-making capacity must be reviewed by a legal officer and psychiatrist or psychologist.[39] The Navy expressly follows general principles of the President's Commission and directs that:

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[33] Letter to Senators Heinz and Glenn from Michael Kerby, Deputy Director, Legislative Liaison (February 13, 1986).

[34] AFR 168–4, paragraph 12–113.

[35] Dept. of the Army Policy Statement on Withdrawal of Life-Sustaining Treatment.

[36] NAVMEDCOM Instruction 6320.16. Consent For Medical Treatment, Para. 6(a).

[37] Enclosure (1) of letter from James F. Goodrich, Acting Secretary of the Navy to Senators Heinz and Glenn, 18 April 1986, at Para 2; *see also* NAVMEDCOM Instruction 6320.16, Para 6(a).

[38] NAVMEDCOM Instruction 6320.2. Para 5, 6, and 7; *see also* NAVMEDCOM Instruction 5420.3A. Establishment of Bioethics Review Committee in Naval Hospitals, Para 8(c).

[39] *Id.*

> In all deliberations, the underlying principle is to attempt to determine the decision the patient would have made if he or she was fully competent and informed.[40]

Department of Health and Human Services

National Institutes of Health (NIH)

The largest single provider of health services in the Department is the Clinical Center of the National Institutes of Health (NIH), a major research facility. The Clinical Center expressly follows the recommendations of the President's Commission and affirms the right of competent patients to forego any treatment, including one that sustains life.[41] Family consent is accepted if the patient has provided written delegation of authority to a specific family member. In the absence of a prior directive, family members' desires concerning treatment of a patient will be given some weight, but are not controlling.[42] To determine whether a patient has the capacity for decision-making, physicians discuss the matter with the patient and family, and also may request psychiatric and neurologic consultation. In addition, physicians may "test" the patient's understanding by posing questions about information that has been provided about the proposed treatment.

The Department of Health and Human Services also operates health facilities through the Indian Health Service and at the Gillis W. Long Hansen's Disease Center, in Louisiana.

Indian Health Service

The Indian Health Service will honor a patient's refusal of treatment, although refusal of a blood transfusion that is considered necessary for preservation of life must be in writing.[43] If, based upon a mental status examination, a patient is found to be incompetent, consent of the natural or legal guardian is accepted (except for sterlization and abortion). Orders not to resuscitate in the event of cardiac or respiratory arrest may be written by an attending physician after consulation with the patient (or, if the patient is incompetent, the patient's family and/or guardian), but only if a consensus is reached regarding resuscitation efforts.[44]

Gillis W. Long Hansen's Disease Center

At the Hansen's Disease (Leprosy) Center, parents or legal guardians may consent to health care on behalf of incompetent patients.[45] Orders not to resuscitate a terminally ill patient must be discussed with the patient, or a representative of the patient, to the extent possible.[46] Differences of opinion concerning resuscitation may be discussed with an ethics committee.

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[40] *Id.* Para 7(b)(2).
[41] Letter from James B. Wyngaarden, M.D., Director, NIH, to Senator John Glenn (Feb. 18, 1986).
[42] *Id.; see also* Clinical Center Policy on Living Wills and Medical Power of Attorney (1985).
[43] 42 C.F.R. Part 35.
[44] Indian Health Service Circular No. 85-1, Instructions Not to Resuscitate Certain Patients Policy (Feb. 28, 1985).
[45] By-Laws, Carville Medical Staff (April 1984), Section 26.
[46] *Id,* Section 33.

Federal Bureau of Prisons [47]

The Federal Bureau of Prisons views its responsibility concerning the inmates in its custody as including decisions concerning their health care. As a result, inmates may not refuse medical care deemed necessary to sustain life or to prevent harm to self or others. Elective treatment may be refused. Family consent on behalf of an incompetent inmate is not sought because decisions regarding necessary treatment are made by the Bureau of Prisons. There are no formal policies or specific procedures for determining the decisionmaking capacity of an inmate.

Veterans Administration

The right to refuse treatment in Veterans Administration hospitals is clear and will be honored, so long as the consequences of refusal have been explained to the patient.[48] The explanation concerning the consequences of refusal must be documented in the medical record. A family member may consent or refuse treatment on behalf of an incompetent patient, in the following order of priority: spouse, adult child, parent, adult sibling.[49] Family consent for procedures such as sterilization, psychosurgery and aversive conditioning (behavior modification) will be accepted only where permitted by state or court authorization.[50]

Orders not to resuscitate a patient may be written only after consulting with the patient, if the patient is competent, and encouraging the patient to discuss the matter with family members.[51] If the patient is incompetent, orders not to resuscitate must be discussed with the patient's surrogate or family members. If the next of kin disagree among themselves, no order not to resuscitate may be written for an incompetent patient unless the patient has provided an advance directive, as discussed later in this report.

2. COURT CASES

Twice in recent years, courts have been asked to determine the right of patients in federal hospitals to refuse life-prolonging treatment. In 1981, a patient suffering from amyotrophic lateral sclerosis ("Lou Gehrig's disease") requested that he be removed from a ventilator. His wife and son objected and VA medical personnel refused to honor his request. The patient sued the Veterans Administration, charging assault and battery, breach of fiduciary duty, and violation of his constitutional right of privacy as well as his common law right to refuse medical treatment.[52] *A federal district court in California held that when a competent patient, informed of the consequences, requests discontinuation of a respirator, refusal of the hospital to honor his wishes is an invasion of his constitutional right of privacy and dignity. The court's order to remove the respirator was stayed, pending an appeal by the Veterans Administration,*

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[47] Letter from Norman A. Carlson, Director, Federal Bureau of Prisons, to Senator John Heinz (Feb. 6, 1986).

[48] VA Manual M-02, paragraph 26.03 (May 16, 1983) and Appendix 26-A.

[49] 38 C.F.R. § 17.34 (1986).

[50] *Id.*

[51] VA Circular No. 10-84-179, Guidelines for "Do Not Resuscitate" (DNR) Protocols Within the VA (Oct. 16, 1984).

[52] *Foster v. Tourtellotte*, No. CV 81-5046-RMT (C.D. Cal. Nov. 16, 17, 1981).

and the patient died (still connected to the machine) before the appeal could be filed. As a result, there is no appellate court decision in this case.

Martha Tune, a 71-year-old widow with terminal cancer asked physicians of Walter Reed Army Medical Center to disconnect her respirator. No one doubted her competence; but the medical staff believed that policies of the Department of the Army prohibited removal of life support even when requested by a competent patient.[53] *When Martha Tune sued, the Federal District Court for the District of Columbia held that competent adult patients in federal medical facilities, who are terminally ill and in Mrs. Tune's circumstances, have the right to have life-support equipment withdrawn.*[54] *The Army did not appeal.*

D. Guardianships, Conservatorships, and Court Orders

All 50 states and the District of Columbia have a mechanism by which courts can appoint a guardian to manage the assets or make personal decisions on behalf of those who have become unable to care for themselves. The statutes and common law principles are grounded in the state's police power and the responsibility of the state, as *parens patriae* (the state acting as parent), to protect those who cannot or will not take care of themselves.

1. WHAT GUARDIANSHIP IS

Guardianship or conservatorship of the *estate* (an individual's property) is available in all 50 states. Although some states use the term "guardianship" while others use "co. servatorship," the duties of both are similar to those of a trustee in managing the assets of a ward. In contrast, guardianship or conservatorship of the person involves fundamental decisions such as where the ward will live (whether at home or in an institution), who will provide necessary care, and the kind of activities in which the ward will be permitted to engage.

The terms *guardian* and *conservator* are often used interchangeably. In a number of states, if a court does not specify a type of guardianship, there is a presumption in favor of "full" guardianship (*i.e.*, of both the person and property).

2. WHY GUARDIANSHIP IS SOUGHT

The intent of guardianship is benevolent: to provide care and decision-making authority for those who cannot manage their own affairs. However, it should not be sought unnecessarily because it can result in substantial deprivation of liberty and property.

Guardianships are usually sought by parties with genuine concern for the needs of the proposed ward. Sometimes, family members seek guardianship when health care providers, fearing legal liability, are fearful of implementing a decision to withhold or with-

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[53] See policy statement of the Acting Surgeon General, Department of the Army (that formerly prohibited the use of living wills and similar directives in Army Military Treatment Facilities) (May 23, 1978) *reprinted in* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*, Appendix I, 520–22 (1983).

[54] *Tune v. Walter Reed Army Medical Center*, 602 F. Supp. 1452 (D.D.C. 1985).

draw treatment. At other times, concerned friends and family of a patient disagree on the best course of action and seek court review to resolve their conflict. Occasionally, health care providers seek court assistance to establish who is responsible for payment or who can provide legally valid informed consent. In addition, some states have laws that require physicians and other health professionals to notify appropriate state or community agencies when they know of an individual who needs guardianship services.

Occasionally, determination of incompetency is sought to subject an unwilling patient to medical treatment. Sometimes a guardian is appointed even when family members are available who have intimate knowledge of the patient's wishes. This may happen because the family members are not closely enough related to bring them within the scope of family consent statutes.

3. HOW THE NEED FOR GUARDIANSHIP IS DETERMINED

Although statutory language and case law vary among the states, a determination of the need for guardianship generally requires two steps. First, the proposed ward must have a specified diagnosis or disability. Second, as a result of that disability, the proposed ward must be unable to make decisions on his or her own behalf. The Uniform Probate Code defines an "incapacitated person" as one "who is impaired by reason of mental illness, mental deficiency, physical illness or disability, advanced age,[55] chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent lacking sufficient understanding or capacity to make or communicate responsible decisions." [56]

Courts frequently appoint a "guardian *ad litem*," usually an attorney, whose responsibility is to represent the proposed ward's interests during the guardianship proceedings. In some states, guardianship decisions require the judge personally to observe the prospective ward; elsewhere, this is discretionary. Courts typically receive testimony from hospital physicians concerning a patient's competency. In states that have adopted the Uniform Probate Code, the court is directed, or has the discretion, to have a court "visitor" interview the patient. The visitor may be a court employee, a representative of a public or private charity, or a staff member of an adult protective service agency. Community resources (such as public health departments, agencies providing services for the elderly, and schools of public health or nursing) can provide additional assistance. A conference of probate judges in Massachusetts has established a specialized panel of guardians *ad litem* to assist courts with questions about life-sustaining treatments.

A serious drawback to many systems is that, even where visits, evaluations, and legal representation have been mandated by law, there often is no provision for paying the professionals who perform the services. That is now the situation in New Jersey following the landmark case involving Claire Conroy. In that state, a proposal to withdraw life-sustaining treatment from a patient in a

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[55] Advocates for the elderly have vigorously protested the use of "advanced age" as a basis for defining incapacity; nevertheless, it remains in the Uniform Code.

[56] Uniform Probate Code § 5–103, 8 U.L.A. 437 (West 1983).

nursing home must be reviewed by the state ombudsman, who is directed to treat every notification as a case of possible abuse. In addition, two independent physicians must confirm the patient's prognosis, but it is not clear who should pay for the physicians' services.

4. WHO MAY BE APPOINTED

If the court finds that a person lacks decision-making capacity, it will appoint a guardian (sometimes referred to as a "committee," even when an individual is appointed). Unfortunately, as the President's Commission observed, guardianship proceedings are typically initiated in response to an individual's inability to manage property and financial matters, and the guardians appointed are often financial institutions or their employees, who are ill-suited for making decisions about personal matters.[57]

A major difficulty is that the person appointed by the court may not be the one the ward would prefer to make health care decisions, even if it is a "close" relative. Indeed, the guardian may be a total stranger, with beliefs and values that differ significantly from those of the ward. Because so many elderly individuals outlive their family (or have none nearby), a number of states have devised a "public guardianship" under which a government agency, rather than an individual, assumes the role of guardian for a ward who has no family member available.

5. THE EFFECTS OF GUARDIANSHIP

The court may grant a guardian a broad range of powers affecting virtually every aspect of a ward's life, such as the management of assets, where and with whom the ward will live, and the granting or withholding of consent for medical treatment. However, courts and legislatures increasingly are recognizing that competence may fluctuate over time, and that patients may have the capacity to make some choices, but not others. Thus, a growing number of states now permit a *limited* or *partial* guardianship, in which decision-making authority is confined to specific areas. Some states allow courts to structure the guardianship authority to fit the needs of an individual ward, while others require only that the guardian's powers be drawn as narrowly as possible. Thus, in some states the appointment of a guardian does not necessarily deprive the ward of all civil rights and personal authority.

Yet, the deprivation of autonomy and self-determination inherent in a finding of even partial incompetency and the appointment of a guardian can be devastating. To varying degrees, it can result in the loss of control over residence, associations, travel, and the freedom to vote, contract or execute a will. Moreover, the rules of discovery in competency proceedings allow for far-reaching inquiry and can be humiliating to the potential ward. One nurse with much experience as a participant in these proceedings writes; "knowledge of such an adjudication can be lethal. [I have] known at least three wards whose physical conditions were not terminal but who refused to eat and died within two weeks of notice that

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[57] President's Commission, *Making Health Care Decisions*, *supra* n.9, at 175.

guardianship had been imposed."[58] On the other hand, appointment of a guardian may make possible some arrangements that are otherwise beyond the ward's reach due to inability to enter into contracts—for example, moving into a retirement community, public housing, or nursing home.

6. THE COST OF GUARDIANSHIP

Unfortunately, the most vulnerable individuals (especially those without substantial assets) often fall through the bureaucratic cracks in the system of social services. Ironically, it may be more difficult to find a guardian, or to institute guardianship proceedings, when life and death questions are at issue than when the problem is one of financial management. Perhaps this is because guardianship proceedings are expensive as well as time-consuming and humiliating.[59]

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[58] B. Nolan, "Functional Evaluation of the Elderly in Guardianship Proceedings," *Law, Medicine and Health Care*, Vol. 12, No. 5 (1984) 210, 217, n.19.

[59] F. Collin, J. Lombard, A. Moses, H. Spitler, *Drafting the Durable Power of Attorney: A Systems Approach* (Sheppard/McGraw Hill, 1984) at 3. One of the authors (J. Lombard) estimates the cost of a guardianship proceeding to be between $2,500 and $5,000 in most cases. Memorandum of John J. Lombard to Senate Special Committee on Aging (February 20, 1986) commenting on a draft of this report.

III. NEW APPROACHES: ADVANCE DIRECTIVES

One way to increase control over what happens in the event of incapacity is to write instructions in advance. Two kinds of advance directives relating to health care are now recognized by law: so-called "living wills" and durable powers of attorney. It is important to bear in mind that advance directives (and the laws authorizing their use) do not create rights; rather, they are mechanisms for exercising the fundamental right to make one's own choices about health care.

There are two important reasons for preparing advance directives. The first is to help ensure that one's wishes will be honored.[60] The second is to protect family members, health care professionals, and others from the stress and potential conflict of making critical decisions without sufficient information concerning an incapacitated patient's preferences. Family members may disagree strongly—and in good faith—concerning a particular decision. Written instructions could spare them considerable pain and guilt by designating who among them should make decisions and by relieving them of the burden of deciding what treatment should be provided.

Advance directives for health care are in some ways similar to wills directing the distribution of property after death. They lift the burden of decisionmaking from the family members by setting forth instructions as to how to proceed, whether it be for care of a person during critical illness, or disposition of bodily organs and property following death. It is a way of extending the right of self-determination even to the time when one is unable to give instructions in person. It is also an expression of care and concern for one's family—to have had the foresight to have taken the time to plan ahead and thus spare them additional pain during what inevitably will be a period of stress. As the courts repeatedly have said, one's right to self-determination with respect to health care decisionmaking is not lost when an individual is no longer capable of making—or expressing—personal choices.

This section describes advance directives and explains some of their current limitations.

A. Living Wills

Many people by now have heard about "living wills." These are documents by which an individual may give directions about health care, to be followed in the event he or she has a terminal

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[60] Even individuals under guardianship or conservatorship can benefit from advance directives for health care. Priority often is given to agents designated under durable powers of attorney when guardians are appointed and, if a different person is serving as guardian or conservator, the agent appointed by the patient generally may still carry out the patient's wishes concerning health care.

illness and is unable to provide further instructions. Although most state laws refer to them as "declarations" or "directives" created pursuant to the state's Natural Death Act, these documents are popularly known as living wills. In this report, the familiar term "living will" is used generically to refer to written instructions concerning health care in the event of terminal illness or irreversible condition. Usually, a living will directs that if death is imminent, the process of dying should not be prolonged, but care necessary to maintain comfort and dignity should be provided while the terminal illness is permitted to take its natural course. By September 1986, living wills had been recognized by legislation enacted in all but twelve states. (See Table 3.)

TABLE 3.—STATES THAT HAD NOT ENACTED NATURAL DEATH ACTS BY SEPTEMBER 1986

Kentucky	Nebraska	Ohio
Massachusetts	New Jersey	Pennsylvania
Michigan	New York	Rhode Island
Minnesota	North Dakota	South Dakota

In New York and New Jersey, written declarations such as living wills have been recognized by the courts as clear and convincing evidence of a patient's wishes that may be implemented by physicians, acting in good faith, without need for additional court proceedings.[61]

It is likely that courts in other states would rule similarly, if the question were presented. As a matter of practice, however, health care providers may well accept living wills as trustworthy evidence of a patient's wishes and implement them, unless there is conflict among family members concerning the appropriateness of foregoing a particular form of treatment. (Of course, family members have no right to override a specific treatment decision made by a patient while competent.)

The major impediment to implementing living wills in the absence of clear, statutory authority is the fear on the part of some physicians and hospital attorneys that patients' families will sue for failure to provide proper care. It is clear that such fears are misplaced, however. No health care provider to date has been subject to sanction for withholding or withdrawing life prolonging treatment based upon a written directive signed by the patient or with the agreement of next of kin.

The closest example of potential liability occurred in 1983 when criminal charges were brought against two California physicians who, with the family's consent, removed life supporting equipment from a terminally ill, comatose patient. But the charges were dismissed by the California Court of Appeal, ruling that physicians, acting in good faith and with family consent, may withdraw life-sustaining treatment even in the absence of a declaration, prepared under the state's Natural Death Act.[62] The court based its ruling on the principle that physicians are not required to continue ther-

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[61] *In the Matter of Selma L. Saunders*, 129 Misc.2d 45, 492 N.Y.S.2d 510 (Sup. Ct. Nassau County, N.Y. July 16, 1985); *In the Matter of Claire Conroy*, 98 N.J. 321, 486 A.2d 1209 (N.J. 1985).

[62] Barber v. Superior Court, 147 Cal.App.3d 1006, 195 Cal. Rptr. 484 (1983).

apy that is useless (i.e., that can not improve the likelihood of recovery).[63]

In fact, health care providers that continue to apply life-sustaining treatment against the expressed wishes of a patient or the patient's family risk liability for wrongful treatment or battery.[64]

1. TYPICAL PROVISIONS

Natural Death Acts typically provide that life-prolonging treatments may be withheld or withdrawn from a patient who has prepared a valid living will (i.e., one that complies with the formal requirements set forth in the statute). Generally, before a living will may be implemented, two physicians (including the attending physician) must certify in writing that the patient is terminally ill, as defined by the Act. In seven states, certification by only one physician is sufficient.[65]

The definition of "terminal illness" varies among the states, but generally requires diagnosis of an irreversible condition that will lead to death; many states add: "with or without the administration of life-sustaining treatment." In many states, death must be "imminent", but "imminent" often is not defined.

The Uniform Rights of the Terminally Ill Act, approved in August 1985 by the National Conference of Commissioners on Uniform State Laws, uses the phrase "terminal condition," as defined as "an incurable or irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death in a relatively short time." (As noted earlier, the Commissioner's approval of a Uniform Act carries with it a recommendation that the Act be adopted by all of the states.) The physicians' certification of terminal illness and the patient's Declaration must both be made part of the medical record.

Natural Death Acts specifically protect health care providers from civil and criminal liability for withholding or withdrawing life-prolonging treatment in compliance with living wills. In addition, the Acts typically state that refusal of life-prolonging treatment by a terminally ill patient does not constitute suicide for insurance or other purposes. In most states, a health care provider who is unwilling to comply with the patient's directive for religious or personal reasons is obliged to try to transfer the patient to the care of another who will comply. In one-third of the states, failure to follow a patient's valid directive, or to transfer the patient to another's care, constitutes unprofessional conduct on the part of the doctor or hospital. In some states, such failure is a misdemeanor—as it is in the Uniform Rights of the Terminally Ill Act.[66]

State laws vary with respect to: (1) requirements for executing a valid living will, and (2) conditions under which a living will may be implemented. As a result, a document that is legally valid in the state where it was signed may not always be as clearly within the statutory protections of other states. It is possible that the inten-

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[63] *Id.*

[64] *Leach* v. *Shapiro*, 13 Ohio App.3d 393, 469 N.E.2d 1047 (1984)

[65] Connecticut, Idaho, Illinois, Indiana, Maine, Montana and Vermont require certification of terminal illness only by the attending physician.

[66] See Section 9(a) of the Act. The entire text of, and accompanying commentary to, the Uniform Rights of the Terminally Ill may be found at Appendix G of this report.

tions of a living will would be given effect despite technical deviations from the form required by a particular state. Nevertheless, uniformity across the states would eliminate uncertainty.

2. HOW TO CREATE A LEGALLY VALID LIVING WILL

Although most states provide a form that may be used to create a living will, only California, Idaho and Oregon require that the form be strictly followed. The remaining states permit individual variations so long as the state's requirements for making a valid living will are satisfied. A sample living will is reproduced at Appendix B of this report.

All states that recognize living wills by statute require that they be signed in the presence of at least two adult witnesses.[67] Because of possible conflicts of interest that may arise, the states usually prohibit at least one (and sometimes both) of those witnesses from including relatives, persons who might be entitled to inherit the person's estate, individuals who have financial responsibility for the person's health care, and individuals who have professional responsibility for the person's health care (such as the physician or employees of the health care facility). A few states require that one witness be the nursing home ombudsman when a nursing home resident signs a living will. (See Table 4.)

Some states require that the living will be notarized, and a few have additional requirements such as filing with a government office. Two states (California and Idaho) require that living wills be reaffirmed after a certain number of years. (See Table 5.)

In some states, a terminally ill patient may make an oral declaration in the presence of witnesses who then sign a written version. Table 5 presents the significant requirements for creating a valid living will in the 39 states that have enacted Natural Death Acts. Only four states (Hawaii, Maine, Maryland and Montana) specifically recognize a living will from another state.

In the Uniform Rights of the Terminally Ill Act, there are no specific qualifications (or disqualifications) for witnesses. Moreover, Section 11 of the Act specifically recognizes the validity of living wills validly executed in other states. This approach simplifies the procedure, solves the problem of using the declaration in a state other than where it was signed, and removes from health care providers the burden of determining whether technical witness requirements have been met.

In two states (California and Oklahoma), a living will is binding only if it is signed *after* a diagnosis of terminal illness has been made.

3. HOW LIVING WILLS ARE PUT INTO EFFECT

Most of the Natural Death Acts require patients to notify their physicians that they have signed a living will and require the physicians to include a copy in the patient's medical record. These requirements have obvious utility. However, sometimes a primary physician is not in charge of the patient's care during a particular

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[67] South Carolina requires three witnesses and a notary. South Carolina Death With Dignity Act, H.B. 2041, 1986 S.C. Acts 127.

hospitalization. This can happen if the patient becomes ill or is involved in an accident while away from home, or if the patient is hospitalized for surgery (in which case the surgeon, not the primary physician, may be the physician in charge). Therefore, it is important to make several copies of a living will that can be given to a hospital or another physician should the need arise. One or two close friends or family members should also be given copies so that they can provide one, if need be.

Once a patient has been diagnosed as terminally ill, and the diagnosis is certified by the required number of physicians, some states require that the patient be informed of the terminal diagnosis before the living will can be implemented.

4. STATUTORY LIMITATIONS ON THE USE OF LIVING WILLS

As previously indicated, Natural Death Acts generally apply only to patients who are "terminally ill." Yet, even after a diagnosis of terminal illness has been made, there may be limitations on the use of a living will. Approximately half the states that have enacted a Natural Death Act prohibit implementation of a living will if the patient is pregnant. (See Table 5.) In addition, almost half the states specifically exclude the provision of nourishment and hydration from the category of "extraordinary care" that may be withheld or withdrawn from a terminally ill patient under the general authority of a living will. (See Table 5.) In such states, whether it is possible for the patient's legal representative to direct that nutritional support be withheld or withdrawn, is not entirely clear. (See section on Nourishment and Hydration, below.) However, a Florida appellate court recently ruled that the Constitutional right to refuse treatment includes the right to have a nasogastric feeding tube removed and such rights may not be limited by legislation. (See *Corbett* v. *D'Allessandro,* No. 85–1052, Fla. App. 2nd Dist., April 18, 1986.)

As noted earlier, living wills valid in one state might not be honored in another if the formal requirements for creating a valid document differ significantly or if the second state has not enacted a Natural Death Act. This is of particular concern in a mobile society.

In addition, there are definitional problems that may frustrate the declarant's intentions. For example, the requirement that a patient be "terminally ill" may present difficulties. Victims of serious accidents or strokes, who are in a coma or persistent vegetative state, are not "terminally ill" as that phrase is defined in most Natural Death Acts and as generally understood; yet such patients may not wish to live for years in a coma if recovery is virtually impossible. Similarly, many individuals suffering from progressive deterioration of various organ systems or the combined effects of degenerative disorders may not want to be kept on life-support systems if they no longer have any awareness of life. Yet, living wills would not apply in their case under most Natural Death Acts.

Similarly, it may not be clear whether a proposed medical treatment should be considered "extraordinary" (and therefore may be foregone) or "supportive" (and therefore must be provided).

Although many Natural Death Acts have used these terms, the President's Commission presented persuasive arguments that the distinction between "ordinary" and "extraordinary" is not useful in this context. One reason is that "extraordinary" has a number of possible meanings, including: very expensive, highly complex, extremely unusual, artificial, or highly invasive. In addition, a particular intervention might be viewed as extraordinary with respect to one patient, but ordinary with respect to another, because of differences in the patients' conditions.[68] A more useful analysis, according to the Commission, is one that weighs the burdens and benefits of a proposed treatment for a particular patient given that patient's medical condition and prognosis at the time a decision must be made.[69] Several courts have since adopted the Commission's reasoning and terminology,[70] as have professional associations.[71]

TABLE 4.—WITNESS REQUIREMENTS FOR DECLARATIONS

State	Witness may not be—					Nursing home patient requires special witness
	Related by blood or marriage	Heir or claimant to the estate	Declarant's physician	Employed by declarant's health care facility	Responsible for declarant's health care costs	
Alabama	X	X			X	
Alaska	X					
Arizona	X	X			X	
Arkansas						
California	X	X	X	X		Patient Advocate or Ombudsman.
Colorado		X	[1] X	[2] X		
Connecticut						
Delaware	X	X		X	X	Patient Advocate or Ombudsman.
District of Columbia	X	X	X	X	X	Patient Advocate or Ombudsman.
Florida	[3] X					
Georgia	X	X	X	X	X	Medical Director.
Hawaii	[4] X		X	X		
Idaho	X	X	X	X		
Illinois	X	X			X	
Indiana	[5] X	X			X	
Iowa						
Kansas	X	X			X	
Louisiana	X	X	X	[2] X		
Maine						
Maryland	X	X	X	X	X	
Mississippi	X	X	X			
Missouri						
Montana						
Nevada	X	X	X	X		
New Hampshire	X	X	X			Medical Director.
New Mexico						
North Carolina	X	X	X	X		
Oklahoma	X	X	X	[2] X	X	
Oregon	X	X	X	X		Individual designated by the Department of Human Resources.

[68] President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego-Life Sustaining Treatment* (1983), at 82–99.

[69] *Id.* at 88–90.

[70] *See, e.g., Barber, supra,* n.62, *Conroy, supra,* n.61.

[71] *See, e.g.,* The Council on Ethical and Judicial Affairs of the American Medical Association, Statement on Withholding or Withdrawing Life Prolonging Treatment (March 15, 1986), reprinted in Appendix H of this report.

TABLE 4.—WITNESS REQUIREMENTS FOR DECLARATIONS—Continued

State	Witness may not be—					Nursing home patient requires special witness
	Related by blood or marriage	Heir or claimant to the estate	Declarant's physician	Employed by declarant's health care facility	Responsible for declarant's health care costs	
South Carolina [6]	X	X	X	X	X	Hospital or nursing home resident requires ombudsman.
Tennessee	X	X	X	X		
Texas	X	X	X	[2] X		
Utah	X	X	X	X	X	
Vermont	X	X	X			
Virginia	X					
Washington	X	X	X	X		
West Virginia	X	X	X	X	X	
Wisconsin	X	X	X	X		
Wyoming	X	X			X	

[1] Or any M.D.
[2] Or copatient.
[3] 1 of 2 witnesses.
[4] Or adoption.
[5] Only parents, spouse and children.
[6] South Carolina requires three witnesses and notary.

TABLE 5.—SPECIAL LIMITATIONS ON DECLARATIONS

State	Not valid during pregnancy	Categorically may not withhold food and fluids	Effective only for given number of years	To be binding, must be signed after terminal diagnosis
Alabama	X			
Alaska	[1] X			
Arizona	[1] X	X		
Arkansas				
California	X		5	X
Colorado	[1] X	X		
Connecticut	X	X		
Delaware	X			
District of Columbia				
Florida	X	X		
Georgia	X	X		
Hawaii	X			X
Idaho				
Illinois	X	X		
Indiana	X	[2] X		
Iowa	[1] X	X		
Kansas	X			
Louisiana				
Maine		X		
Maryland	X	X		
Mississippi	X			
Missouri	X	X		
Montana	[1] X			
Nevada	X			
New Hampshire	X	X		
New Mexico				
North Carolina				
Oklahoma		X		X
Oregon		[3] X		
South Carolina	X	X		

TABLE 5.—SPECIAL LIMITATIONS ON DECLARATIONS—Continued

State	Not valid during pregnancy	Categorically may not withhold food and fluids	Effective only for given number of years	To be binding, must be signed after terminal diagnosis
Tennessee		X		
Texas	X			
Utah	X	[4]X		
Vermont				
Virginia				
Washington	[3]X			
West Virginia				
Wisconsin	X	X		
Wyoming	X	X		

[1] If fetus could develop to point of live birth.
[2] May not withhold "appropriate" nourishment and hydration.
[3] May withhold if patient cannot tolerate.
[4] Unless declarant specifically authorizes.

5. THE ISSUE OF NOURISHMENT AND HYDRATION

One example of the difficulty in applying distinctions between ordinary vs. extraordinary care, or aggressive treatment vs. supportive or comfort care, is the issue of whether artificial nourishment and hydration may be withdrawn from a terminally ill or comatose patient. (Artificial nourishment would include, for example, nasogastric feeding tubes, intravenous solutions, and gastrostomy tubes.)

All of the courts that have addressed the problem of withdrawing artificial feeding have taken the position that the replacement of a nonfunctioning digestive system by mechanical means (such as a nasogastric feeding tube) is no different legally from the mechanical replacement of a nonfunctioning respiratory system. Thus, the courts have held, artificial nourishment (like any other form of medical treatment) may be withheld or withdrawn from an incapacitated patient if the burdens imposed by it outweigh the benefits received by the patient, given that patient's current condition and prognosis.[72] Most recently, the Supreme Court of Massachusetts ruled that the wife of a permanently comatose, 49-year-old former fireman and emergency medical technician (with the concurrence of their five adult children) may carry out his previously stated wishes and withdraw the tube feedings that had sustained him through three years of comatose existence.[73]

Some people feel strongly that there is something qualitatively different about the provision of food and drink that provokes strong opposition to the idea of withholding them from someone who is ill. They emphasize that the provision of nourishment is a

[72] For a description of recent cases involving artificial nourishment, see B. Mishkin, "Courts Entangled in Feeding Tube Controversies," 1(4) *Nutrition in Clinical Practice* 209–215 (August 1986). Recent cases include: *Corbett* v. *D'Alessandro*, 487 So.2d 368 (Fla. App. 1986) (*rev. denied*); *In re Nancy Ellen Jobes*, No. C-4971-85E (Super. Ct. N.J., April 23, 1986); *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (N.J. 1985); *In re Hier*, 18 Mass. 200, 464 N.E.2d 959, *review denied*, 392 Mass. 1102, 465 N.E.2d 261 (1984); *Barber* v. *Superior Court of California*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983).

[73] *Brophy* v. *New England Sinai Hospital*, ——— N.E.2d ———, 398 Mass. 417 (1986).

fundamental element of family responsibility, that food and drink are central to communal celebrations and an integral part of many religious observances. Therefore, as at least one bioethicist has suggested, it may serve humanity to pay attention to the "moral revulsion" some feel about withholding nutrition, while accepting that ventilators may be withdrawn.[74]

Others suggest that it should not be obligatory to provide artificial nourishment and hydration, in the following rare situations:

(1) The procedures that would be required are so unlikely to achieve improved nutritional and fluid levels that they could be correctly considered futile; (2) The improvement in nutritional and fluid balance, though achievable, could be of no benefit to the patient; and (3) The burdens of receiving the treatment may outweigh the benefit.[75]

They would agree, however, that even in the situations described, it may be important to provide nourishment and hydration if that is what the patient wants, or would want, or if interested persons (family, friends, or caregivers) "feel that such procedures affirm important values." [76] Finally, those who believe it may be acceptable, in limited cases, to forego artificial nourishment and hydration, caution that in most cases, "patients will be best served by providing nutrition and fluids" and that the presumption should be that nutrition and fluids will be provided.[77]

The American Medical Association's Council on Ethical and Judicial Affairs recently issued the following statement on the subject:

> Life prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefit of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained.[78]

The AMA's position, as stated, is consistent with that of the President's Commission.

In the end, decisions of this sort are inescapably personal. Therefore, it is important to indicate one's own feelings on the matter in an advance directive and to arrange for someone to serve as an advocate in this regard, should the need arise. The section on Durable Powers of Attorney explains how this may be done.

6. HOW TO REVOKE A LIVING WILL

A living will may always be revoked. This is consistent with the principle that consent to treatment is an ongoing process and a patient may always have a change of mind. Generally, living wills

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[74] D. Calahan, "On Feeding the Dying," *Hastings Center Report* (October 1983) at p. 22.

[75] J. Lynn and J. Childress, "Must Patients Always Be Given Food and Water?", 13(5) *Hastings Center Report* 17-21 (Oct. 1983); J. Lynn (ed.), *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water* (1986).

[76] Lynn and Childress in *Hastings Center Rpt., supra* n. 75, at 20.

[77] *Id.* at 21.

[78] American Medical Association, Council on Ethical and Judicial Affairs, Statement on Withholding or Withdrawing Life Prolonging Treatment (March 15, 1986); R. Barry, F. Rouse, F. Davila and N.W. Dickey, "Withholding or Withdrawing Treatment," (letters) *JAMA*, Vol. 256, No. 4, 469-471 (July 25, 1986).

may be revoked by an oral declaration of the patient. Even in the one state (Mississippi) that requires living wills to be filed with the Bureau of Vital Statistics, and that requires revocations to be similarly witnessed and filed, an oral revocation is sufficient if the patient is physically unable to sign the revocation document, have it witnessed, and file it with the Bureau.

7. RECOGNITION OF LIVING WILLS IN FEDERAL FACILITIES

The Air Force, the Navy, the Veterans Administration, the Indian Health Service and the Hansen's Disease Center honor living wills to the extent permitted by the state in which their facilities are located.[79] In the Veterans Administration, a living will that lacks legal effect in the host state may nevertheless be entered into a patient's medical record to be considered, along with other factors, in determining the patient's wishes.[80]

The Clinical Center at the National Institutes of Health (NIH) accepts living wills prepared in any state, so long as the maker was 18 years or older and the document was signed and witnessed by at least two persons (who also were 18 years of age or older). No notary is required.

The Army has no stated policy regarding living wills although, as noted earlier, a competent patient may direct that life-sustaining procedures be withdrawn or withheld.

The Federal Bureau of Prisons also has no policy concerning living wills. However, such documents presumably would have no effect since the Bureau does not permit inmates to refuse treatment necessary to sustain life.

B. Durable Powers of Attorney

Powers of attorney traditionally have been used in the context of commercial transactions and the management of property. For example, one could delegate power of attorney to a trusted friend, relative, or lawyer in order to give that person authority to complete a transaction (such as purchase or sale of a house) if one's own presence were not possible.[81] Or, one could give power of attorney to a financial advisor to manage investments.

An individual must be a competent adult to give such important authority to another. And, since a power of attorney may always be revoked, historically it was necessary for one to remain competent in order to have the power remain in effect (because, it was thought, one must always competently choose not to revoke the power). Clearly, such an arrangement would defeat the purpose of arranging for another to take over in the event of one's own incapacity (since the power of attorney would become void just at the time it was designed to take effect).

To overcome the operation of law that automatically revoked the effectiveness of a power of attorney when the maker became in-

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[79] Letter from Michael Kerby, *supra* n.33; enclosure (1) of letter from James F. Goodrich, *supra* n.37; VA Circular 10-85-79 (May 14, 1985); Indian Health Service Circular No. 85-1 (Feb. 28, 1985); Carville Medical Staff By-Laws, Section 33(8).

[80] VA Circular 10-85-79 (May 14, 1985), section 3(c)

[81] There are a few exceptions to the general rule. For example, in the District of Columbia, real estate may not be transferred through a power of attorney.

competent, state legislatures have enacted laws permitting powers of attorney to be *durable*—in other words, to *endure* even if the maker's competency does not. To create a durable power of attorney, the document must merely state that it is intended to be durable, or that the power created will not be affected by the incapacity of the principal (the person writing the document).

1. POWERS OF ATTORNEY FOR HEALTH CARE

Although powers of attorney were developed and used traditionally in areas of commercial transactions and transfers of property, most state statutes provide that a power of attorney may be either "general" (*i.e.*, for making any and all decisions in a variety of areas) or "specific" (*i.e.*, limited to a particular area of concern, transaction, or time frame). The President's Commission and many legal scholars have taken the position that in the absence of a statutory limitation on the use of powers of attorney, nothing should prevent their use for appointing individuals to make health care decisions.[82] The applicability of powers of attorney for health care decisions has been affirmed by statute in a small number of states.

No court has ruled on the validity of powers of attorney in this context, however; therefore, no one can say with absolute certainty that a power of attorney for health care would be implemented by a court, if the question were posed. Nevertheless, since courts generally will accept clear and convincing evidence of a patient's wishes in matters concerning health care, the probability is high that a court would accept an incapacitated patient's designation of a proxy health care decision maker through a durable power of attorney.[83] The Supreme Court of New Jersey, ruling in the case of Claire Conroy, indicated that it would recognize the authority of a durable power of attorney for health care created in conformity with New Jersey's general durable power of attorney statute. (*Conroy*, *supra* n.72, 486 A. 2d at 1229).

2. ADVANTAGES OF DURABLE POWERS OF ATTORNEY

Durable powers of attorney are more flexible, and apply to more situations, than living wills. They also permit the individual (rather than a court) to decide who should make decisions on his or her behalf in the event of incapacity.

Although the word "attorney" is used, powers of attorney may be given to virtually anyone (family member, trusted friend, clergy, or financial advisor) including attorneys.[84]

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[82] President's Commission, *Deciding to Forego Life-Sustaining Treatment*, *supra* n.68, at 146–147; F. Collin, J. Lombard, A. Moses and H. Spitler, *Drafting the Durable Power of Attorney*, *supra* n.59, at 24–25.

[83] The Attorney General of New York recently suggested that a durable power of attorney is "an uncertain vehicle" for delegating general authority for making health care decisions; however, he added that such a document could be used to delegate to an agent the responsibility for communicating an individual's decision to decline medical treatment under certain circumstances. Op. Atty. Gen. No. 84-F16 (Dec. 28, 1984).

A special task force convened by the Governor of New York recently recommended legislation that would authorize written delegations of authority appointing individuals to make health care decisions in the event of later incapacity. New York Task Force on Life and the Law, *Do not Resuscitate Orders: The Proposed Legislation and the Report of the New York State Task Force on Life and the Law* (April 1986).

[84] In Florida, however, only certain family members may be appointed under a "family durable power of attorney."

Durable powers of attorney are recognized everywhere in the United States except the District of Columbia.[85] As a result, a durable power of attorney created in one state is more likely to be honored in another.

In addition, durable powers of attorney can be used by individuals who want life-prolonging treatments *continued*, as well as by those who prefer (as in most living wills) to forego such treatment.

Finally, durable powers of attorney can be used to make decisions on behalf of individuals who are not terminally ill, but who are incapable of making their own decisions because of some other reason (for example, a serious accident, a permanent loss of consciousness, an incapacitating degenerative illness). Durable powers of attorney can be applied to decisions about all forms of health care (for example, whether a nursing home resident should have dental surgery or undergo an invasive diagnostic procedure); they are not limited to questions about life prolonging treatment.

For all of these reasons, durable powers of attorney are much more flexible documents than living wills.

3. HOW TO CREATE A DURABLE POWER OF ATTORNEY

Durable powers of attorney are relatively simple to create. They may be either broad (delegating the power to act in a number of areas, both financial and personal) or they may be very specific (*e.g.*, limited to decisions concerning health care).

To create a durable power of attorney for health care, it is generally possible to follow a standard form and merely fill in the blanks so long as other formalities set forth in state laws are followed.[86] (See Appendix C.) It is advisable to designate one or more successor agents in case the primary agent is unavailable or unable to act. For example, a spouse is often designated as the primary agent, but both husband and wife could be injured in a common accident. If both are too seriously injured to make their own decisions or to decide for each other, then someone else will have to make decisions on behalf of both. Thus, individuals typically designate first a spouse, then either an adult child or a brother or sister. One could also designate a close friend or advisor. The most important consideration is that individuals appoint people in whom they have confidence and who can be relied upon to act according to the interests and values of the person who appointed them.

Because of possible conflicts of interest or the appearance of impropriety, it is recommended that the following *not* be designated as an agent for making health care decisions: the primary physician, or any other practitioner with professional responsibility for the patient's health care, and any employee of a health care facility (such as a hospital, nursing home, home health agency or hospice) in which the individual is, or is likely to be, receiving care.

Durable powers of attorney must be witnessed and notarized as required by state law. Because of the variations among state laws

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[85] A bill authorizing durable powers of attorney in the District of Columbia was approved by the D.C. City Council on Dec. 16, 1986, and awaits the Mayor's signature. Bill 6-7 (District of Columbia Guardianship, Protective Proceedings and Durable Power of Attorney Act of 1986).

[86] For example, California requires that a nursing home ombudsman witness a power of attorney for health care prepared by a resident of a skilled nursing facility. (See Appendix E to this report.)

(described below) and the possibility that a power of attorney may need to be used in a state different from the one in which it was prepared, it is often suggested that the document be witnessed and notarized, to cover all eventualities.

4. VARIATION AMONG STATE LAWS

A Uniform Durable Power of Attorney Act was approved in 1979 by the National Commissioners on Uniform Laws; however, only a handful of states have adopted it as a statutory means of recognizing powers of attorney that survive the incompetence or disability of the maker. Most states have incorporated language from the Uniform Probate Code providing that powers of attorney will not be affected by the incapacity of the individual conveying the power (*i.e.*, the "principal").[87] Several states (notably California, Connecticut, New York, and Rhode Island) have their own formulations. (See Appendix D.)

The Uniform Durable Power of Attorney provisions adopted from the Uniform Probate Code, however, do not assure uniform requirements for creating these documents. That is because the "durable" provision is merely added onto pre-existing requirements for creating valid powers of attorney—and those requirements vary among the states as to whether a notary is required, whether the power of attorney must be filed with a government office, and (in the case of South Carolina) how many witnesses are required. (See Table 6.)

—In California, Connecticut, Minnesota, New York and Rhode Island, a special statutory form is provided, however, it may be modified to meet individual needs.

—In the following states, a power of attorney must be notarized: Arkansas, California, Connecticut, Minnesota, Missouri, New York, North Carolina, and South Carolina.

—In Oklahoma and Wyoming, a power of attorney must be approved by a judge of the state district court.

—In the following states, a power of attorney must be filed with a specified government office: Arkansas, Missouri, North Carolina, Oklahoma, South Carolina and Wyoming. (See Table 6.)

In a society as mobile as ours, lack of uniformity concerning procedural requirements raises the possibility that advance planning will be frustrated by technical differences among state laws.

TABLE 6.—SPECIAL REQUIREMENTS FOR CREATING DURABLE POWERS OF ATTORNEY

State	Notary required	Filing required	Other
Arkansas	Yes (or approval of Probate Court).	Probate Court	
California [1]	Yes (or signed by two witnesses).		If patient is in nursing home, one witness must be patient advocate or ombudsman.
Connecticut	Yes		Must be accompanied by statutory notice or signed by an attorney. Must be accompanied by statutory notice.

[87] See §§ 5-501 and 5-502 of the Uniform Probate Code, 8 U.L.A. 513 (1983).

TABLE 6.—SPECIAL REQUIREMENTS FOR CREATING DURABLE POWERS OF ATTORNEY—Continued

State	Notary required	Filing required	Other
Florida	No		Only a spouse, parent, adult child, sibling, niece or nephew may be appointed.
Minnesota	Yes		
Missouri	Yes	Recorder of deeds	
New York	Yes		Must be accompanied by statutory notice.
North Carolina	Yes	Register of deeds (copy with clerk of Superior Court).	
Oklahoma	No	Clerk of State District Court	Must be approved by judge of state District Court.
Rhode Island [1]	No		At least one witness must not be related by blood, marriage or adoption and must not be entitled to any part of the maker's estate.
South Carolina	Yes	Register of Mesne Conveyance.	Requires three witnesses.
Wyoming	No	Clerk of District Court (copy with clerk of county court where principal resides).	Must be approved by judge of state District Court.

[1] California and Rhode Island have statutory forms for durable powers of attorney for health care which include a cautionary notice to persons executing the document.

5. RECOGNITION OF DURABLE POWERS OF ATTORNEY IN FEDERAL HEALTH CARE FACILITIES

Durable powers of attorney are recognized explicitly in the policies of only two federal agencies: the Air Force and the NIH Clinical Center. Air Force policy is to recognize durable powers of attorney if they are validly executed and enforceable according to the laws in the state in which the medical facility is located.

Under a "trial policy," the NIH Clinical Center not only recognizes but actively encourages the use of durable "Medical Powers of Attorney." The Medical Power of Attorney must be signed, witnessed, and notarized. Forms, information and assistance are available to patients. A copy of the power of attorney is included in the medical record of inpatients and the original is given to the patient or a family member.

The Navy accepts health care decisions made by persons authorized under state law to consent on behalf of another, and therefore implicitly recognizes durable powers of attorney to the extent they are authorized by state law.

The Army permits parents to execute powers of attorney giving authority to others to make decisions concerning the health care of minor children, if not prohibited by the laws of the host state.

The Veterans Administration, Indian Health Service, and Hansen's Disease Center have no policies concerning durable powers of attorney.

The Federal Bureau of Prisons also has no policy concerning durable powers of attorney and, presumably would not honor such documents in view of the Bureau's position that it is responsible for making decisions concerning the health care of incompetent inmates in its custody.

6. WHAT TO DO AFTER SIGNING A DURABLE POWER OF ATTORNEY

As with living wills, an important part of signing a durable power of attorney is what happens next. Those who have been appointed as agents should discuss with the maker as many aspects of health care as they can imagine might require attention. It is especially important, given the developing state of the law regarding nutrition and hydration, to discuss one's feelings and intentions about artificial feeding in addition to other forms of life-sustaining treatment to make sure that written instructions about such matters are fully understood. It would also be useful to discuss possible placement in different kinds of health care facilities, such as hospices and nursing homes. For persons already in a nursing home, it is important for those making decisions to understand the resident's feelings about being transferred to a hospital, in specific circumstances. Agents should also understand how the individual feels about orders not to resuscitate (DNR orders) in the event of cardiac or respiratory arrest.

In addition to discussions with the named agents, discussions should be initiated with one's primary physician and family members. Those who have not been named as agents should understand that decisionmaking authority has been delegated to particular individuals and what the practical effects of that delegation are.

Finally, copies of the durable power of attorney should be given to the named agents, the primary physician, and close family members. Extra copies should be kept for medical records in health care facilities.

C. Anatomical Gifts

Although somewhat different from living wills and durable powers of attorney, donations of bodily tissues and organs following death may also be arranged in advance. In 1968, the National Commissioners on Uniform State Laws approved the Uniform Anatomical Gift Act which permits competent adults to indicate, in advance, their intent to donate organs (such as corneas, kidneys, hearts, and livers) at the time of their death.[88] The law permits the donor to sign a legally valid document authorizing such gifts, and no additional permission by family members or others is required. The procedure is designed to permit the directive of the donor to be implemented automatically, at the time of death, without consulting family members.

In many ways, the organ donor laws are similar to laws requiring probate courts to follow a deceased person's instructions for distribution of property (as set forth in a legally valid will)—whether or not family members and other heirs agree with that distribution. The actual implementation of the Uniform Anatomical Gift Act has differed from the intent of the drafters, however, and practices could be revised to be more consistent with the intent of the statutes.

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[88] Uniform Anatomical Gift Act, 8A U.L.A. 15 (1983).

1. HOW TO MAKE AN ANATOMICAL GIFT

The Uniform Anatomical Gift Act was designed to eliminate the confusion of having a variety of laws around the country and to enlarge the class of organ donors to the extent possible.[89] Under the Act, any person 18 years of age or older and of sound mind may "give all or any part of his body for any purpose specified [by the Act], the gift to take effect upon death." (See Section 2 of the Act which is reproduced at Appendix K.) Anatomical gifts may be made either by a will or by a document other than a will. In either case, the gift becomes effective upon the death of the donor. If the gift is made through a traditional will, it is effective automatically at the death of the donor, without going through probate. (See Section 4 of the Act.) The gift may be made to a specified donee (recipient), but it need not be.

The Commissioners' Commentary (accompanying the text of the Uniform Law) urges states to print forms or notices on driver's licenses to simplify the process of organ donation, and 45 states have done so. Wallet-sized organ donor cards are also widely distributed by private organizations such as the National Kidney Foundation, to be signed and witnessed under the provisions of the Uniform Anatomical Gifts Act.

In the absence of a document indicating the deceased's intentions, members of the family (in the following priority) may make an organ donation: (1) the spouse; (2) an adult son or daughter; (3) either parent; (4) an adult brother or sister; (5) a guardian of the person of the decedent at the time of his death; or (6) any other person authorized or under obligation to dispose of the body.

No family member may authorize an anatomical gift if there is knowledge of a contrary intention on the part of the deceased or known opposition by a member of the same or a prior class. (See Section 2 of the Act.) A few states have enacted laws requiring hospitals to discuss possible organ donation with families of dying patients.

2. HOW DEATH IS DETERMINED

Some individuals fear that organs will be removed before the patient is "really dead." However, the Act protects against such action by requiring that the physician who declares time of death or who certifies death *not* be the physician who removes any tissue or organs for transplantation. (See Section 7(b).) This is intended to exclude the attending physician from taking any part in the transplant procedures. In addition, detailed guidelines explain how to determine that death has occurred.

Before respirators were devised, death was defined merely as the cessation of heartbeat and respiration. Now, respirators can maintain the heart and lungs even when the entire brain has ceased to function. Today, most states recognize an alternative definition of death based on the total and irreversible cessation of all brain function. In the last two decades, a number of statutory variations on this theme were enacted, all with the same intent. Unfortunate-

[89] *Id.;* Comment to Section 2 at 35.

ly, the variations left the disconcerting impression that a person could be simultaneously alive in one state and dead in another, depending upon the statutory language.

To remedy this situation, the President's Commission for the Study of Ethical Problems in Medicine proposed a model law, the Uniform Determination of Death Act.[90] It was drafted in consultation with the American Bar Association, the American Medical Association, and the National Conference of Commissioners on Uniform State Laws. All three of these groups have endorsed the model act as preferable to versions they supported in the past.

More than a dozen states have adopted the Uniform Determination of Death Act, providing a uniform definition of death for purposes of criminal law, tort law, family law, insurance law, and the disposition of an estate. Although revising the law permits death to be determined on the basis of brain-related criteria, it is still the physician's responsibility to determine whether an individual patient's brain has ceased to function totally and irreversibly. The President's Commission published guidelines, developed by a group of prominent physicians and scientists, for determining death according to brain criteria through the use of up-to-date tests and technologies.[91] These guidelines, applied by physicians, provide a means of confirming that death has occurred even when machines are pumping air and blood through organs incapable of functioning on their own. (The text of the Guidelines appears in Appendix L of this Report.)

3. WHAT HAPPENS AT THE TIME OF DEATH

Under the Uniform Anatomical Gift Act, an organ donation becomes effective (vests) upon the death of the donor. It is only after the organs have been removed that the remains may be given over to the custody of the surviving spouse, next of kin, or other person under obligation to dispose of the body. (See Section 7.) If the gift is of the entire body, the recipient "may, subject to the terms of the gift, authorize embalming and the use of the body in funeral services." (Id.)

The Uniform Anatomical Gift Act does not provide for family members to be asked to approve a donor's gift or to be given an opportunity to defeat the donor's intent. Yet, that is the current custom. Hospitals uniformly seek the consent of next of kin to carry out the wishes of the donor and apparently seldom proceed without such consent.[92]

In a survey conducted recently by the Gallup Organization, hospitals said they seek family consent in order to avoid legal liability.[93] Yet, Section 7(c) of the Act states clearly that:

> A person who acts in good faith in accord with the terms of this Act or with the anatomical gift laws of another state [or foreign country] is not liable for damages in any

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[90] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Defining Death* (Washington, 1981) at 119.

[91] *Id.*, Appendix F at 159-166; *reprinted in* 246(19) JAMA 2184-186 (November 13, 1981).

[92] H. Schwartz, "Bioethical and Legal Considerations in Increasing the Supply of Transplantable Organs: From UAGA to 'Baby Fae,'" 10(4) *Amer. J. Law & Med.* 397, 406 (Winter 1985).

[93] *Id.*

> civil action or subject to prosecution in any criminal proceeding for his act.

Moreover, the commentary to the Act states that at the time of the donor's death, the donee (recipient) has absolute ownership of the body, if he accepts the gift, and that:

> The entire section 7 merits genuinely liberal interpretation to effectuate the purpose and intent of the Uniform Act, that is, to encourage and facilitate the important and ever increasing need for human tissue and organs for medical research, education and therapy, including transplantation.

According to the Centers for Disease Control, of the approximately 20,000 persons who are declared dead each year on the basis of brain-related criteria and who are potential organ donors, organs are obtained from only approximately 2,000. This is due in part to logistical problems; for example, kidneys must be used within 48 hours of the donor's death and other organs can be maintained for only a few hours. However, available organs may be lost merely because health care providers fail to find—or honor—the decedent's donor card, or are reluctant to raise the issue with the decedent's family.[94] A number of states have enacted laws requiring hospital personnel to inquire about organ donor cards and to seek permission for organ donation from next of kin when a potential donor dies.

Physicians and hospital administrators should educate themselves—and then, educate the families of their patients—about the legal rights and obligations created by a valid anatomical gift. One reason individuals make donations in advance is to save their family from having to make difficult decisions at a time of extreme stress. Such individuals have the right to expect that their legally valid donations will be given effect. Their families should be informed by attending physicians that the deceased made an anatomical gift and that the law not only permits, but requires, the hospital to honor that gift. That is the purpose of the Uniform Anatomical Gift Act.

Most recently, the United States Congress passed legislation requiring hospitals participating in Medicare and Medicaid to establish written policies and procedures to identify potential organ donors while, at the same time, encouraging discretion and sensitivity to the circumstances, views and beliefs of the potential donor's family.[95]

D. Conclusion

This report has emphasized the importance of communication (both written and oral) in health care decisionmaking, and has described ways in which advance directives can help to assure that

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[94] B. Merz, "The Organ Procurement Problem: Many Causes, No Easy Solutions," 254 (23) JAMA 3285 (Dec. 20, 1985).

[95] The Sixth Omnibus Budget Reconciliation Act, Pub. L. No. 99-509, § 9318 (adding new § 1138 to Title XI of the Social Security Act), H.R. 5300, 99th Cong., 2d Sess., *Cong. Rec.* H11317, H11356 (daily ed. Oct. 17, 1986).

individual choices will be honored, even during periods of physical or mental incapacity.

Although most states now recognize both living wills and durable powers of attorney, state laws differ as to requirements for witnesses and notaries. Because we live in a mobile society, confidence in the usefulness of advance directives would be enhanced if states would honor documents prepared in other jurisdictions. It would be even better for all states to adopt the same requirements for preparing living wills and durable powers of attorney. Uniform recognition of advance directives by federal agencies would complete the picture.

There is a clear need for additional education by professional schools, professional societies, public interest groups, and advocates. This report is designed to assist in a larger effort of legislation, education, and individual counseling so that ultimately, every individual who so desires will be able to plan ahead for decisions about their health care.

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V. RESOURCES

American Association of Retired Persons, 1909 K Street, N.W., Washington, D.C. 20049, (202) 728-4375.

American Bar Association, Commission on Legal Problems of the Elderly, 1800 M Street, N.W., Washington, D.C. 20036, (202) 331-2297.

Amercian Civil Liberties Union, 132 West 43rd Street, New York, New York 10036, (212) 944-9800.

American Health Care Association, 1200 15th Street, Washington, D.C. 20005, (202) 833-2050.

American Hospital Association, 840 North Lake Shore Drive, Chicago, Ill. 60611, (312) 280-6000.

Committee Against Intractable Pain, P.O. Box 9553, Washington, D.C. 20016, (202) 944-8140.

Concern for Dying, 250 West 57th Street, New York, New York 10107, (212) 246-6962.

Hastings Center (Institute of Society, Ethics and the Life Sciences), 360 Broadway, Hastings-on-Hudson, New York 10706, (914) 478-0500.

Kennedy Institute of Ethics, Center for Bioethics—Library, Georgetown University, Washington, D.C. 20057, (202) 625-2386, (800) MED-ETHX (reference service).

Legal Counsel For the Elderly, 1331 H Street, N.W., Washington, D.C. 20005, (202) 234-0970.

National Council on the Aging, Inc., Post Office Box 7227, Ben Franklin Station, Washington, D.C. 20044, (202) 479-1200.

National Health Law Program, 2401 Main Street, Santa Monica, California 90405, (213) 392-4811.

National Hospice Organization, 1901 North Fort Myer Drive (Suite 902), Arlington, Virginia 22209, (703) 243-5900.

National Senior Citizens Law Center, 2025 M Street, N.W. Suite 400, Washington, D.C. 20036, (202) 887-5280.

Older Women's League, 1325 G Street, N.W., Lower Level, Washington, D.C. 20005, (202) 543-0694.

Society for the Right to Die, 250 West 57th Street, New York, New York 10107, (212) 246-6973.

The Living Bank (Registry and Referral Service for people wishing to donate tissues, organs, or bodies for transplantation or research), (800) 528-2971, (713) 528-2971 (In Texas, only).

VI. CHECKLIST FOR ADVISORS

Patient/Client: _____

1. Has patient/client prepared:
—living will ☐
—durable power of attorney ☐
—organ donor card ☐

a. If yes, check if copies are attached:
living will ☐
durable power of attorney ☐
organ donor card ☐

b. If yes, but no copies are attached, contact the following who have copies:

_____
name

_____
address

_____
telephone number

_____
documents

_____
name

_____
address

_____
telephone number

_____
documents

2. Would client like information about advance directives?

a. Materials provided on _____
(date)

b. Patient/client will return to discuss and prepare documents on _____

c. If no specific date set, telephone after _____ to set up appointment.
Patient/client's telephone number:
_____ (home)
_____ (office)

3. Individuals named in documents (or otherwise to make health care decisions for patient/client in case of incapacity:

a. **Primary Decision-Maker**
name: _____
relationship to patient/client: _____
address: _____
_____
telephone: _____ (home)
_____ (office)

b. **Alternate or Successor Decision-Maker(s)**
name: _____
relationship to patient/client: _____
address: _____
_____
telephone: _____ (home)
_____ (office)

name: _____
relationship to patient/client: _____
address: _____
_____
telephone: _____ (home)
_____ (office)

c. **Primary Physician**
name: _____
office address: _____
_____
telephone: _____ (home)
_____ (office)

4. Staff person who filled out this checklist:

_____
name

_____
date

APPENDIX A

LIVING WILL LEGISLATION

Alabama Natural Death Act, Ala. Code § 22-8A-1 (1981).

Alaska Rights of the Terminally Ill Act, S.B. 140, 1986 Alaska Sess. Laws 957, to be codified at Alaska Stat. § 18.12.010.

Arizona Medical Treatment Decision Act, Ariz. Rev. Stat. Ann. § 36-3201 (1985).

Arkansas Death with Dignity, Ark. Stat. Ann. § 82-3801 (1977).

California Natural Death Act, Cal. Health & Safety Code § 7185 (1976).

Colorado Medical Treatment Decision Act, Colo. Rev. Stat. § 15-18-101 (1985).

Connecticut Death with Dignity Act, Public Act No. 85-606 (1985).

Delaware Death with Dignity Act, Del. Code Ann. tit. 16, § 2501 (1982).

District of Columbia Natural Death Act of 1981, D.C. Code Ann. § 6-2421 (1982).

Florida Life Prolonging Procedure Act, Fla. Stat. Ann. § 765.01 (1984).

Georgia Living Wills Act, Ga. Code Ann. § 31-32-1 (1984), as amended by Act 1350, 1986 Ga. Laws 585.

Hawaii Act Relating to Medical Treatment Decisions, Hawaii Rev. Stat. § 327D (1986).

Idaho Natural Death Act, Idaho Code § 39-4501 (1977) as amended by H.B. No. 498, 1986 Idaho Sess. Laws 573.

Illinois Living Will Act, Ill. Ann. Stat. ch. 110½ § 701 (Smith-Hurd 1984).

Indiana Living Wills and Life-Prolonging Procedures Act, Ind. Code § 6-8-11 (1985).

Iowa Right to Decline Life-Sustaining Procedures Act, Iowa Code ch. 144A.1 (1985).

Kansas Natural Death Act, Kan. Stat. Ann. § 65-28, 101 (1979).

Louisiana Life-Sustaining Procedures, La. Rev. Stat. Ann. § 40:1299.58.1 (1984).

Maine Living Will Act, Me. Rev. Stat. Ann. tit. 22, ch. 710a (1985).

Maryland Life-Sustaining Procedures Act, Md. Health General Code Ann. § 5-601 (1985).

Mississippi Act, Miss. Code Ann. § 41-41-101 (1984).

Missouri Act, Mo. Rev. Stat. § 459.010 (1985).

Montana Living Will Act, Mont. Code An. § 50-9-101 (1985).

Nevada Withholding or Withdrawal of Life-Sustaining Procedures, Nev. Rev. Stat. § 449.540 (1977).

New Hampshire Living Wills Act, N.H. Rev. Stat. Ann. ch. 137-H (1985).

New Mexico Right to Die Act, N.M. Stat. Ann. § 24-7-1 (1978).

North Carolina Right to Natural Death Act, N.C. Gen. Stat. § 90-320 (1977, amend. 1979, 1981, 1983).

Oklahoma Natural Death Act, Okla. Stat. tit. 63, §3101 (1985).

Oregon Rights with Respect to Terminal Illness, Or. Rev. Stat. § 97.050 (1977, amend. 1983).

South Carolina Death with Dignity Act, H.B. 2041, P. 36 S.C. Acts 127.

Tennessee Right to a Natural Death Act, Tenn. Code Ann. § 32-11-101 (1985).

Texas Natural Death Act, Tex. Stat. Ann. art. 4590h (1977, amend. 1983).

Utah Personal Choice and Living Will Act, Utah Code Ann. § 75-2-1101 (1985).

Vermont Terminal Care Document, Vt. Stat. Ann. tit. 18, § 5251 (1982).

Virginia Natural Death Act, Va. Code Ann. § 54-325.8:1 (1983).

Washington Natural Death Act, Wash. Rev. Code Ann. § 70.122.010 (1979).

West Virginia Natural Death Act, W. Va. Code § 16-30-1 (1984).

Wisconsin Natural Death Act, Wisc. Stat. § 154.01, as amended by 1985 Wisc. Act 199 (April 10, 1986).

Wyoming Act, Wyo. Stat. § 33-26-144 (1984).

APPENDIX B

[SAMPLE]*

"LIVING WILL"

DECLARATION

Declaration made this _____ day of _____, 198___.

I, _____, being of sound mind, willfully and voluntarily make known my desires that my dying shall not be artificially prolonged under the circumstances set forth below, and do declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two (2) physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort, care or to alleviate pain.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed _____

Address _____

_____

I believe the declarant to be of sound mind. I did not sign the declarant's signature above for or at the direction of the declarant. I am at least 18-years of age and am not related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession of the _____ or under any will of the declarant or codicil thereto, or directly financially responsible for declarant's medical care. I am not the declarant's attending physician, an employee of the attending physician, or an employee of the health facility in which the declarant is a patient.

Witness _____

Address _____

_____

Witness _____

Address _____

_____

ss.:

Before me, the undersigned authority, on this _____ day of _____, 198___, personally appeared _____, _____, and _____, known to me to be the Declarant and the witnesses, respectively, whose names are signed to the foregoing instrument, and who, in the presence of each other, did subscribe their names to the attached Declaration (Living Will) on this date, and that said Declarant at the time of execution of said Declaration was over the age of eighteen (18) years and of sound mind.

[SEAL]

My commission expires:

_____

Notary Public

*Check requirements of individual state statute.

Source: President's Commission for the Study of Ethical Problems in Medicine and Biobehavioral Research. "Deciding To Forego Life Sustaining Treatment." U.S. Government Printing Office, pages 414-415.

APPENDIX C

[SAMPLE]*

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

I, _____

hereby appoint

_____

name

_____

home address

_____

_____

_____

home telephone number

_____

work telephone number

as my agent to make health care decisions for me if and when I am unable to make my own health care decisions. This gives my agent the power to consent to giving, withholding or stopping any health care, treatment, service, or diagnostic procedure. My agent also has the authority to talk with health care personnel, get information, and sign forms necessary to carry out those decisions.

If the person named as my agent is not available or is unable to act as my agent, then I appoint the following person(s) to serve in the order listed below:

1. _____

name

_____

home address

_____

_____

_____

home telephone number

_____

work telephone number

2. _____

name

_____

home address

_____

_____

_____

home telephone number

_____

work telephone number

By this document I intend to create a power of attorney for health care which shall take effect upon my incapacity to make my own health care decisions and shall continue during that incapacity.

My agent shall make health care decisions as I direct below or as I make known to him or her in some other way.

(a) STATEMENT OF DESIRES CONCERNING LIFE-PROLONGING CARE, TREATMENT, SERVICES, AND PROCEDURES:

_____

_____

_____

_____

_____

_____

(b) SPECIAL PROVISIONS AND LIMITATIONS:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

(Continued)

*Check requirements of individual state statute.

Source: Barbara Mishkin, Hogan and Hartson.

BY SIGNING HERE I INDICATE THAT I UNDERSTAND THE PURPOSE AND EFFECT OF THIS DOCUMENT.

I sign my name to this form on _____ (date)

My current home address: _____

_____

_____

(You sign here)

WITNESSES

I declare that the person who signed or acknowledged this document is personally known to me, that he/she signed or acknowledged this durable power of attorney in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed as agent by this document, nor am I the patient's health care provider, or an employee of the patient's health care provider.

First Witness

Signature: _____

Home Address: _____

Print Name: _____

Date: _____

Second Witness

Signature: _____

Home Address: _____

Print Name: _____

Date: _____

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I further declare that I am not related to the patient by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of his/her estate under a will now existing or by operation of law.

Signature: _____

Signature: _____

I further declare that I am not related to the patient by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of his/her estate under a will now existing or by operation of law.

Signature: _____

Signature: _____

APPENDIX D

STATUTORY FORM POWER OF ATTORNEY (MINNESOTA)

§ 523.23. Statutory short form of general power of attorney; formal requirements; joint agents.

Subdivision 1. Form.

The use of the following form in the creation of a power of attorney is lawful, and, when used, it shall be construed in accordance with the provisions of sections 523.23 and 523.24:

Notice: THE POWERS GRANTED BY THIS DOCUMENT ARE BROAD AND SWEEPING. THEY ARE DEFINED IN SECTION 523.24 IF YOU HAVE ANY QUESTIONS ABOUT THESE POWERS, OBTAIN COMPETENT ADVICE. THE USE OF ANY OTHER OR DIFFERENT FORM OF POWER OF ATTORNEY DESIRED BY THE PARTIES IS ALSO PERMITTED. THIS POWER OF ATTORNEY MAY BE REVOKED BY YOU IF YOU LATER WISH TO DO SO. THIS POWER OF ATTORNEY AUTHORIZES THE ATTORNEY-IN-FACT TO ACT FOR YOU BUT DOES NOT REQUIRE THAT HE OR SHE DO SO.

Know All Men by These Presents, which are intended to constitute a STATUTORY SHORT FORM POWER OF ATTORNEY pursuant to Minnesota Statutes, section 523.23:

That I _____

_____

_____ (insert name and address of the principal) do hereby appoint

_____

_____

_____

(insert name and address of the attorney-in-fact, or each attorney-in-fact, if more than one is designated) my attorney(s)-in-fact to act (jointly).

Note: If more than one attorney-in-fact is designated and the principal wishes each attorney-in-fact alone to be able to exercise the power conferred, delete the word "jointly." Failure to delete the word "jointly" will require the attorneys-in-fact to act unanimously.)

First: In my name, place and stead in any way which I myself could do, if I were personally present, with respect to the following matters as each of them is defined in section 523.24:

[To grant to the attorney-in-fact any of the following powers, make a check or "x" in the line in front of each power being granted. To delete any of the following powers, do not make a check or "x" in the line in front of the power. You may, but need not, cross out each power being deleted with a line drawn through it (or in similar fashion). Failure to make a check or "x" in the line in front of the power will have the effect of deleting the power unless the line in front of the power of (*o*) is checked or x-ed.]

Check or "x"

_____ (A) real property transactions;
_____ (B) tangible personal property transactions;
_____ (C) bond, share, and commodity transactions;
_____ (D) banking transactions;
_____ (E) business operating transactions;
_____ (F) insurance transactions;
_____ (G) beneficiary transactions;
_____ (H) gift transactions;
_____ (I) fiduciary transactions;
_____ (J) claims and litigation;
_____ (K) family maintenance;
_____ (L) benefits from military service;
_____ (M) records, reports, and statements;
_____ (N) all other matters;
_____ (O) all of the powers listed in (A) through (N) above.

Second: [You must indicate below whether or not this power of attorney will be effective if you become incompetent. Make a check or "x" in the line in front of the statement that expresses your intent.]

_____ This power of attorney shall continue to be effective if I become incompetent. It shall not be affected by my later disability or incompetency.

_____ This power of attorney shall not be effective if I become incompetent.

Third: [You must indicate below whether or not this power of attorney authorizes the attorney-in-fact to transfer your property directly to himself or herself. Make a check or "x" in the line in front of the statement that expresses your intent.]

____ This power of attorney authorizes the attorney-in-fact to transfer property directly to himself or herself.

____ This power of attorney does not authorize the attorney-in-fact to transfer property directly to himself or herself.

In Witness Whereof I have hereunto signed my name this _____ day of _____, 19____.

_____

(Signature of Principal)

(Acknowledgment)

Specimen Signature of Attorney(s)-in-Fact

_____

_____

APPENDIX E

DURABLE POWER OF ATTORNEY FOR HEALTH CARE DECISIONS

(California Civil Code Sections 2410–2443)

WARNING TO PERSON EXECUTING THIS DOCUMENT

THIS IS AN IMPORTANT LEGAL DOCUMENT. IT CREATES A DURABLE POWER OF ATTORNEY FOR HEALTH CARE. BEFORE EXECUTING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

1. THIS DOCUMENT GIVES THE PERSON YOU DESIGNATE AS YOUR ATTORNEY-IN-FACT THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU. THIS POWER IS SUBJECT TO ANY LIMITATIONS OR STATEMENT OF YOUR DESIRES THAT YOU INCLUDE IN THIS DOCUMENT. THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU MAY INCLUDE CONSENT, REFUSAL OF CONSENT, OR WITHDRAWAL OF CONSENT TO ANY CARE, TREATMENT, SERVICE, OR PROCEDURE TO MAINTAIN, DIAGNOSE, OR TREAT A PHYSICAL OR MENTAL CONDITION. YOU MAY STATE IN THIS DOCUMENT ANY TYPES OF TREATMENT OR PLACEMENTS THAT YOU DO NOT DESIRE.

2. THE PERSON YOU DESIGNATE IN THIS DOCUMENT HAS A DUTY TO ACT CONSISTENT WITH YOUR DESIRES AS STATED IN THIS DOCUMENT OR OTHERWISE MADE KNOWN OR, IF YOUR DESIRES ARE UNKNOWN, TO ACT IN YOUR BEST INTERESTS.

3. EXCEPT AS YOU OTHERWISE SPECIFY IN THIS DOCUMENT, THE POWER OF THE PERSON YOU DESIGNATE TO MAKE HEALTH CARE DECISIONS FOR YOU MAY INCLUDE THE POWER TO CONSENT TO YOUR DOCTOR NOT GIVING TREATMENT OR STOPPING TREATMENT WHICH WOULD KEEP YOU ALIVE.

4. UNLESS YOU SPECIFY A SHORTER PERIOD IN THIS DOCUMENT, THIS POWER WILL EXIST FOR SEVEN YEARS FROM THE DATE YOU EXECUTE THIS DOCUMENT AND, IF YOU ARE UNABLE TO MAKE HEALTH CARE DECISIONS FOR YOURSELF AT THE TIME WHEN THIS SEVEN-YEAR PERIOD ENDS, THIS POWER WILL CONTINUE TO EXIST UNTIL THE TIME WHEN YOU BECOME ABLE TO MAKE HEALTH CARE DECISIONS FOR YOURSELF.

5. NOTWITHSTANDING THIS DOCUMENT, YOU HAVE THE RIGHT TO MAKE MEDICAL AND OTHER HEALTH CARE DECISIONS FOR YOURSELF SO LONG AS YOU CAN GIVE INFORMED CONSENT WITH RESPECT TO THE PARTICULAR DECISION. IN ADDITION, NO TREATMENT MAY BE GIVEN TO YOU OVER YOUR OBJECTIONS, AND HEALTH CARE NECESSARY TO KEEP YOU ALIVE MAY NOT BE STOPPED IF YOU OBJECT.

6. YOU HAVE THE RIGHT TO REVOKE THE APPOINTMENT OF THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU BY NOTIFYING THAT PERSON OF THE REVOCATION ORALLY OR IN WRITING.

7. YOU HAVE THE RIGHT TO REVOKE THE AUTHORITY GRANTED TO THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU BY NOTIFYING THE TREATING PHYSICIAN, HOSPITAL, OR OTHER HEALTH CARE PROVIDER ORALLY OR IN WRITING.

8. THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU HAS THE RIGHT TO EXAMINE YOUR MEDICAL RECORDS AND TO CONSENT TO THEIR DISCLOSURE UNLESS YOU LIMIT THIS RIGHT IN THIS DOCUMENT.

9. THIS DOCUMENT REVOKES ANY PRIOR DURABLE POWER OF ATTORNEY FOR HEALTH CARE.

10. *IF THERE IS ANYTHING IN THIS DOCUMENT THAT YOU DO NOT UNDERSTAND, YOU SHOULD ASK A LAWYER TO EXPLAIN IT TO YOU.*

1. DESIGNATION OF HEALTH CARE AGENT

I, _____

_____
(Insert your name)

do hereby designate and appoint: Name: _____

Address: _____

_____

Telephone Number: _____

as my attorney-in-fact to make health care decisions for me as authorized in this document.

(Insert the name and address of the person you wish to designate as your attorney-in-fact to make health care decisions for you. None of the following may be designated as your attorney-in-fact: (1) your treating health care provider, (2) an employee of your treating health care provider, (3) an operator of a community care facility, or (4) an employee of an operator of a community care facility.)

2. CREATION OF DURABLE POWER OF ATTORNEY FOR HEALTH CARE

By this document I intend to create a durable power of attorney by appointing the person designated above to make health care decisions for me as allowed by Sections 2410 to 2443, inclusive, of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity.

3. GENERAL STATEMENT OF AUTHORITY GRANTED

In the event that I am incapable of giving informed consent with respect to health care decisions, I hereby grant to the attorney-in-fact named above full power and authority to make health care decisions for me before, or after my death, including: Consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition, subject only to the limitations and special provisions, if any, set forth in Paragraph 4 or 6.

4. SPECIAL PROVISIONS AND LIMITATIONS

(By law, your attorney-in-fact is not permitted to consent to any of the following: Commitment to or placement in a mental health treatment facility, convulsive treatment, psycho-surgery, sterilization, or abortion. If there are any other types of treatment or placement that you do not want your attorney-in-fact to have authority to give consent for or other restriction you wish to place on his or her attorney-in-fact's authority, you should list them in the space below. If you do not write in any limitations, your attorney-in-fact will have the broad powers to make health care decisions on your behalf which are set forth in Paragraph 3, except to the extent that there are limits provided by law.)

In exercising the authority under this durable power of attorney for health care, the authority of my attorney-in-fact is subject to the following special provisions and limitations:

_____

_____

_____

_____

5. DURATION

I understand that this power of attorney will exist for seven years from the date I execute this document unless I establish a shorter time. If I am unable to make health care decisions for myself when this power of attorney expires, the authority I have granted my attorney-in-fact will continue to exist until the time when I become able to make health care decisions for myself.

I wish to have this power of attorney end before seven years on the following date: _____

6. STATEMENT OF DESIRES

(With respect to decisions to withhold or withdraw life sustaining treatment, your attorney-in-fact must make health care decisions that are consistent with your known desires. You can, but are not required to, indicate your desires below. If your desires are unknown, your attorney-in-fact has the duty to act in your best interests; and, under some circumstances, a judicial proceeding may be necessary so that a court can determine the health care decision that is in your best interests. If you wish to indicate your desires, you may INITIAL the statement or statements that reflect your desires and/or write your own statements in the space below.)

(If the statement reflects your desires, initial the box next to the statement.)

1. I desire that my life be prolonged to the greatest extent possible, without regard to my condition, the chances I have for recovery or long term survival, or the cost of the procedures. (_____)

2. If I am in a coma which my doctors have reasonably concluded is irreversible, I desire that life sustaining or prolonging treatments or procedures *not* be used. (_____)

3. If I have an incurable or terminal condition or illness and no reasonable hope of long term recovery or survival, I desire that life sustaining or prolonging treatments *not* be used. (_____)

4. I do not desire treatment to be provided and/or continued if the burdens of the treatment outweigh the expected benefits. My attorney-in-fact is to consider the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of the possible extension of my life. (_____)

(If you wish to change your answer, you may do so by *drawing* an "X" through the answer you do not want, and circling the answer you prefer.)

OTHER OR ADDITIONAL STATEMENTS OF DESIRES: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

7. DESIGNATION OF ALTERNATE ATTORNEY-IN-FACT

(You are not required to designate any alternative attorney-in-fact but you may do so. Any alternative attorney-in-fact you designate will be able to make the same health care decisions as the attorney-in-fact designated in Paragraph 1 above in the event that he or she is unable or unwilling to act as your attorney-in-fact. Also, if the attorney-in-fact designated in Paragraph 1 is your spouse, his or her designation as your attorney-in-fact is automatically revoked by law if your marriage is dissolved.)

If the person designated in Paragraph 1 as my attorney-in-fact is unable to make health care decisions for me, then I designate the following persons to serve as my attorney-in-fact to make health care decisions for me as authorized in this document, such persons to serve in the order listed below:

A. First Alternative Attorney-in-fact

Name: _____

Address: _____

_____

Telephone Number: _____

B. Second alternate Attorney-in-fact

Name: _____

Address: _____

_____

Telephone Number: _____

8. PRIOR DESIGNATIONS REVOKED

I revoke any prior durable power of attorney for health care.

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY.)

I sign my name to this Statutory Short Form Durable Power of Attorney for Health Care on _____

_____ at
(Date)

_____,
(City)

_____,
(State)

_____
(Signature)

(THIS POWER OF ATTORNEY WILL NOT BE VALID FOR MAKING HEALTH CARE DECISIONS UNLESS IT IS EITHER (1) SIGNED BY AT LEAST TWO QUALIFIED WITNESSES WHO ARE PERSONALLY KNOWN TO YOU AND WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC IN CALIFORNIA.)

CERTIFICATE OF ACKNOWLEDGMENT OF NOTARY PUBLIC

(You may use acknowledgment before a notary public instead of the statement of witnesses.)

State of California)
) ss.
County of _____)

On this ___ day of _____, in the year ____, before me, _____
(here insert name of notary public)

personally appeared _____
(here insert name of principal)

personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is subscribed to this instrument, and acknowledged that he or she executed it. I declare under penalty of perjury that the person whose name is subscribed to this instrument appears to be of sound mind and under no duress, fraud, or undue influence.

NOTARY SEAL _____
(Signature of Notary Public

STATEMENT OF WITNESSES

(You should carefully read and follow this witnessing procedure. This document will not be valid unless you comply with the witnessing procedure. If you elect to use witnesses instead of having this document notarized, you must use two qualified adult witnesses. None of the following may be used as a witness:

(1) A person you designate as the attorney-in-fact,
(2) A health care provider,
(3) An employer of a health care provider,
(4) The operator of a community care facility,
(5) An employer of an operator of a community care facility.

At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury under the laws of California that the principal is personally known to me, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney-in-fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, nor an employee of an operator of a community care facility.

Signature: _____

Print Name: _____

Residence Address: _____

_____

_____

Date: _____

Signature: _____

Print Name: _____

Residence Address: _____

_____

_____

Date: _____

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I declare under penalty of perjury under the laws of California that I am not related to the principal by blood, marriage, or adoption, and to the best of my knowledge I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature: _____

Signature: _____

SPECIAL REQUIREMENTS

(Special additional requirements must be satisfied for this document to be valid if (1) you are a patient in a skilled nursing facility or (2) you are a conservatee under the Lanterman-Petris-Short Act and you are appointing the conservator as your agent to make health care decisions for you.)

1. If you are a patient in a skilled nursing facility (as defined in Health and Safety Code Section 1250(c)) at least one witness must be a patient advocate or ombudsman. The patient advocate or ombudsman must

sign the witness statement *and* must also sign the following declaration.

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and am serving as a witness as required by subdivision (a) (2)A of Civil Code 2432.

Signature: _____

Print Name: _____

Address: _____

_____

_____

Date: _____

2. If you are a conservatee under the Lanterman-Petris-Short Act (of Division 5 of the Welfare and Institutions Code) and you wish to designate your conservator as your agent to make health care decisions, you must be represented by legal counsel. Your lawyer must sign the following statement.

I have advised my client _____ (Name) concerning his or her rights in connection with this matter and the consequences of signing or not signing this durable power of attorney and my client, after being so advised, has executed this durable power of attorney.

Name: _____

Print Name: _____

Address: _____

_____

_____

Date: _____

COPIES: You should retain an executed copy of this document and give one to your attorney-in-fact. The power of attorney should be available so a copy may be given to your health care providers.

66-265 O - 87 - 3

APPENDIX F

UNIFORM LAW COMMISSIONERS' MODEL HEALTH-CARE CONSENT ACT

Section

1. Definitions.
2. Individuals Who May Consent to Health Care.
3. Individuals Incapable of Consenting.
4. Individuals Who May Consent to Health Care for Others.
5. Delegation of Power to Consent to Health Care for Another.
6. Health-care Representative: Appointment, Qualification, Powers, Revocation and Responsibility.
7. Court-Ordered Health Care or Court-Ordered Appointment of a Representative.
8. Disqualification of Authorized Individuals.
9. Limitations of Liability.
10. Availability of Medical Information.
11. Effect on Existing State Law.
12. Severability.
13. Uniformity of Application and Construction.
14. Short Title.
15. Repeal.
16. Time of Taking Effect.

Law Review Commentaries

Uniform and Model Acts in 1980 (part 1). Maurice H. Merrill. 52 Okl.B.J. 677 (1981).

§ 1. Definitions

As used in this [Act]:

(1) "Adult" means an individual [18] or more years of age.

(2) "Health care" means any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition.

(3) "Health-care provider" means a person who is licensed, certified or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

(4) "Minor" means an individual who is not an adult.

(5) "Person" means an individual, corporation, business trust, estate, trust, partnership, association, government, governmental subdivision or agency, or any other legal entity.

COMMENT

The age of 18 is bracketed in the definition of an adult (subsection (1)) so that states with a different age for achieving adult status may insert whatever age is appropriate.

Health care (subsection (2)) includes any care, treatment, service or procedure to diagnose or treat a physical or mental condition. The term is broader in scope than medical care and includes care and treatment which is lawful to practice under state law, for instance, nursing care.

Since the definition of health care is broader in scope than medical care, there is a need to limit the coverage of the Act so that the rendition of routine care by family members would not be within its coverage. One limitation on the scope of the Act is found in the definition of a health-care provider in subsection 3. That definition excludes those who are not licensed, certified or otherwise authorized to render health care. Hence, the rendition of simple care by a family member to one who is ill at home would not be covered by this Act while that same treatment would be covered if provided in a hospital.

Library References

Assault and Battery ⟨⟩ 2.
Physicians and Surgeons ⟨⟩ 15(8).
C.J.S. Assault and Battery §§ 2 to 4, 6 to 8.
C.J.S. Physicians and Surgeons § 48.

§ 2. Individuals Who May Consent to Health Care

Unless incapable of consenting under Section 3, an individual may consent to health care for himself if he is:

(1) an adult; or

(2) a minor and

(i) is emancipated;

(ii) has attained the age of [14] years and, regardless of the source of his income, is living apart from his parents or from an individual in loco parentis and is managing his own affairs.

from: 9 Uniform Laws Ann. (West Supp. 1985).

(iii) is or has been married;

(iv) is in the military service of the United States; or

(v) is authorized to consent to the health care by any other law of this State.

COMMENT

Section 2 describes those individuals who may consent to health care for themselves.[1] All adults, unless disqualified by Section 3, may consent to health care. These two provisions basically restate the common law with regard to consent by adults. At common law minors were not presumed to be competent to consent to health care. However, there are certain status exceptions, both statutory and common law, which render a minor capable of consenting. Section 2(2) is a compilation of the more widely recognized exceptions to the traditional requirement of consent by a parent or guardian which permit a minor, unless disqualified by Section 3, to consent to health care for himself as if he were an adult.

The exceptions are based on the assumption that a minor who has made the described decisions or taken the described actions in his life has demonstrated his capacity to make decisions concerning his health care. The emancipated minor exception is widely recognized in case law and in the statutes of more than thirty states. See Wilkins, *Children's Rights: Removing the Parental Consent Barriers to Medical Treatment of Minors*, 1975 Arizona St L J 31, 59(1975). Paragraph (2)(ii) is an explicit emancipation provision based on objective criteria which will not require a formal adjudication of emancipation. The age is bracketed, but the age of 14 is a reasonable age when coupled with the other requirements of this paragraph.

Other objective criteria which courts and state legislatures have accepted as showing a minor's maturity to make decisions affecting his health are marriage and service with the armed forces. (See, e.g., Ind Ann Stat 16–8–4–1 (Burns 1973).) Once a minor has satisfied any of these criteria he may consent to health care for himself as if he were an adult.

In addition to the status exceptions permitting consent by minors, many legislatures have created additional exceptions authorizing minors to consent to treatment for specific conditions or diseases without regard to their status. For instance, 45 states presently allow minors to obtain treatment for venereal disease without parental consent. One or more states permit minors to consent to the following forms of health care:

(1) health care necessary to diagnose or treat pregnancy;

(2) health care necessary to diagnose or treat venereal disease;

(3) health care necessary to diagnose or treat alcohol or drug dependency or abuse;

(4) psychiatric or psychological counseling;

(5) health care necessary for the performance of an abortion;

(6) health care necessary for counseling in the use of contraceptive devices; and

(7) health care necessary for the performance of any type of sterilization.

Paragraph 2(v) of this Act leaves intact those state laws which permit a minor to consent to one or more specific health-care procedures, regardless of whether the minor meets the status exceptions of paragraph 2.

Library References

Assault and Battery ⟸ 2, 11.
Physicians and Surgeons ⟸ 15(8).
C.J.S. Assault and Battery §§ 2 to 4, 6 to 8, 16, 17.
C.J.S. Physicians and Surgeons § 48.

§ 3. Individuals Incapable of Consenting

An individual otherwise authorized under this [Act] may consent to health care unless, in the good faith opinion of the health-care provider, the individual is incapable of making a decision regarding the proposed health care.

COMMENT

Section 3 uses the phrase incapable of consenting as opposed to incompetency. This choice is deliberate. Incompetency in American law carries the connotation of permanency and is often thought to involve an adjudicative declaration. However, a person may be **de jure** competent when in fact he is incapable of making a decision regarding his own health care. An otherwise competent adult who has been rendered unconscious in an accident is at that time **de facto** incompetent or incapable of making a decision regarding proposed health care.

[1] While the language of Section 2 is cast in terms of an authorization to consent, that necessarily means that one authorized to consent may also refuse consent or withdraw consent to a course of health care once given.

Section 3 is phrased negatively as the law presumes that adults, and under certain circumstances minors as well, are capable of making decisions unless there is some determination of a contrary status. The determination called for in Section 3 is to be made by the health-care provider, and the standard is whether the individual is incapable of making a decision regarding the proposed health care. If the individual is capable of making a decision, the health-care provider must abide by that decision.

Custom suggests and necessity dictates that the initial determination that one is incapable of consenting rest with the health-care provider. Section 3 in recognition of necessity legitimates that custom. Unlike the decision to invoke the emergency exception to the requirement of informed consent which has the effect of bypassing consent altogether, a decision that one is incapable of consenting merely shifts the decision regarding the rendition of health care to a third party. This is an important difference for the health-care provider's decision is *ex necessitae* a "low visibility" one. Any decision to bypass the patient by deciding that he is incapable of making a decision endangers the values of individualism and personal autonomy. What is needed in any such decision is a proper combination of deference to professional judgment and health-care values on the one hand and respect for personal autonomy and individualism on the other. Reposing the ultimate decision to proceed with medical treatment in a third party should assure that values of personal autonomy and individualism receive proper consideration.

The requirement that the individual be incapable of engaging in decision-making is consistent with the underlying notion of consent. A unique human characteristic is the power to make decisions. The language of Section 3 focuses on the ability of one to make a decision as opposed to the content of a health-care decision. A decision to refuse a specific course of treatment may be based on moral or religious grounds. An individual who refuses treatment because he has consistently relied on prayer for healing in accordance with his religious tradition is capable of making his own health-care decisions. A decision to refuse treatment made under those circumstances should be honored by a health-care provider.

The uncertainties of medical practice and the decision to be made do not make precise statements of the test for determining incapacity easy. However, the context in which the decision is made and the effect of such a decision render the lack of precision less onerous.[1] The health-care provider who decides that one is incapable of consenting must then turn to another who is charged with making the ultimate treatment decision in the best interest of the patient.

Library References

Mental Health ⟹331.
C.J.S. Insane Persons § 98 et seq.

§ 4. Individuals Who May Consent to Health Care For Others

(a) If an individual incapable of consenting under Section 3 has not appointed a health-care representative under Section 6 or the health-care representative appointed under Section 6 is not reasonably available or declines to act, consent to health care may be given:

(1) by a guardian of his person, a representative appointed under Section ", or a representative designated or appointed under other law of this State; or

(2) by a spouse, parent, adult child, or adult sibling, unless disqualified under Section 8, if there is no guardian or other representative described in paragraph (1) or he is not reasonably available or declines to act, or his existence is unknown to the health-care provider.

(b) Consent to health care for a minor not authorized to consent under Section 2 may be given:

(1) by a guardian of his person, a representative appointed under Section ", or a representative designated or appointed under other law of this State;

(2) by a parent or an individual in loco parentis, if there is no guardian or other representative described in paragraph (1) or he is not reasonably available or declines to act, or his existence is unknown to the health-care provider; or

(3) by an adult sibling of the minor, if a parent or an individual in loco parentis is not reasonably available, declines to act, or his existence is unknown to the health-care provider.

(c) An individual delegated authority to consent under Section 5 has the same authority and responsibility as the individual delegating the authority.

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[1] See A. Meisel, The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking, 1979 Wis.L.Rev. 413, 452, 472–473.

(d) A person authorized to consent for another under this section shall act in good faith and in the best interest of the individual incapable of consenting.

COMMENT

Section 4 authorizes designated persons to exercise health-care decision-making powers for individuals who cannot consent for themselves and who have not appointed a health-care representative to act on their behalf as authorized in Section 6. If a health care representative has been appointed and is willing to act, that preempts the operation of this section.

Subsection (a) is concerned with adults and minors authorized to consent under Section 2. It sets forth an order of priority among substitute decision-makers. The first priority is given to individuals appointed by a court, a guardian or an individual appointed under Section ". The second priority class is the family. Within this class, the spouse, parents, adult children and adult siblings are ranked equally. Any member of the class is authorized to act. Any decision establishing priority among family members would be largely arbitrary. The objective is to have someone who has a close personal relationship with the patient and who will consider his best interest acting for him. If one of those authorized to act disagrees with the decision of another who has been designated a proxy decision maker, that person can seek formal judicial appointment to act for the one incapable of consenting. However, an objector would be required to show that the other authorized decision-maker was not acting in the patient's best interest. (See Section ".)

Subsection (b) authorizes substitute decision-makers for minors who are not authorized to consent under Section 2. The first priority is given to court-appointed officials. If the parents are alive, it is unlikely that there would be a court-appointed guardian and the parents would have first priority. If there is no court-appointed official and if the parents are unavailable, any adult brother or sister of the minor is authorized to make health-care decisions.

Family members authorized to consent for one incapable of consenting under this section may delegate their decisional authority to another. The person to whom authority is delegated under Section 5 has the same priority to act for the patient as the delegating individual.

One authorized by this section to act for another must act in good faith and in the best interest of the individual incapable of consenting.

Library References

Husband and Wife ⟨⟩1
Mental Health ⟨⟩236
Parent and Child ⟨⟩1
C.J.S. Husband and Wife § 1 et seq.
C.J.S. Insane Persons § 85.
C.J.S. Parent and Child §§ 2 to 4, 10.

§ 5. Delegation of Power to Consent to Health Care for Another

(a) An individual authorized to consent to health care for another under Section 4(a)(2), 4(b)(2) or 4(b)(3) who for a period of time will not be reasonably available to exercise the authority may delegate the authority to consent during that period to another not disqualified under Section 8. The delegation must be in writing and signed and may specify conditions on the authority delegated. Unless the writing expressly provides otherwise, the delegate may not delegate the authority to another.

(b) The delegant may revoke the delegation at any time by notifying orally or in writing the delegate or the health-care provider.

COMMENT

Section 5 permits a limited delegation of authority to consent for another. Family members authorized to consent for another under Section 4 may delegate their decisional authority.

This provision should be helpful in situations in which parents want to delegate health-care decision-making to a temporary custodian of their children, for instance when parents plan to be away or when a child is at camp. This section follows closely Section 5-104 of the Uniform Probate Code.

Library References

Mental Health ⟨⟩179, 236.
C.J.S. Insane Persons §§ 49, 85.

§ 6. Health-care Representative: Appointment; Qualification; Powers; Revocation and Responsibility

(a) An individual who may consent to health care under Section 2 may appoint another as a health-care representative to act for the appointor in matters affecting his health care.

(b) A health-care representative appointed under this section must be an individual who may consent to health care under Section 2.

(c) An appointment and any amendment thereto must be in writing, signed by the appointor and a witness other than the health-care representative and accepted in writing by the health-care representative.

(d) The appointor may specify in the writing terms and conditions considered appropriate, including an authorization to the health-care representative to delegate the authority to consent to another.

(e) The authority granted becomes effective according to the terms of the writing.

(f) The writing may provide that the authority does not commence until, or terminates when, the appointor becomes incapable of consenting. Unless expressly provided otherwise, the authority granted in the writing is not affected if the appointor becomes incapable of consenting.

(g) Unless the writing provides otherwise, a health-care representative appointed under this section who is reasonably available and willing to act has priority to act for the appointor in all matters of health care.

(h) In making all decisions regarding the appointor's health care, a health-care representative appointed under this section shall act (i) in the best interest of the appointor consistent with the purposes expressed in the appointment and (ii) in good faith.

(i) A health-care representative who resigns or is unwilling to comply with the written appointment may exercise no further power under the appointment and shall so inform (i) the appointor, (ii) the appointor's legal representative, if one is known, and (iii) the health-care provider, if the health-care representative knows there is one.

(j) An individual who is capable of consenting to health care may revoke: (i) the appointment at any time by notifying the health-care representative orally or in writing, or (ii) the authority granted to the health-care representative by notifying the health-care provider orally or in writing.

COMMENT

Section 6 is designed to extend the concept of patient autonomy by permitting a person to transfer his health care decision-making power to another. Many individuals who are competent to make health care decisions nevertheless want to delegate this decisional authority to a relative or friend. In addition, in the event they are rendered incapable of consenting, many people want the assurance that some other individual whom they trust will make health-care decisions on their behalf.

It is generally thought that if one cannot or does not exercise his own decisional authority in health-care matters this authority should be placed in the hands of the state (i.e., a court), a health-care provider or the next of kin. Any of these choices may be seen as a restriction on autonomous choice. Leaving this authority in the hands of a court when there are other alternatives available is particularly vexing because it allows the state a measure of control over individuals to which it has no obvious moral right and for which it has no special expertise. Section 6 provides an alternative. The decision to allow the transfer of authority rests on the principle of the basic human need of self determination and individual autonomy. The patient himself can designate the person who is to make these health-care decisions. Section 6 does not prescribe the nature of the decision-making relationship between the appointing individual and the person appointed. The appointing individual has the opportunity to engage in moral discourse with his agent, and to specify in the document the terms and the conditions of the appointment.

Subsection (h) provides that a health-care representative must act in the best interest of the appointor consistent with the purposes expressed in the appointment and in good faith. Cases often purport to draw a distinction between a best interest and substituted judgment standard. (Compare In re Guardianship of Pescinski, 67 Wis.2d 4, 226 N.W.2d 180 (1975) (best interest) with In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976) (substituted judgment)). Yet the two terms reflect not so much a difference in concept as a difference in emphasis. The standard of best interest is generally thought to incorporate a concept of objective reasonableness with reference to the interests of society and others while the substituted judgment standard focuses on the interest of the particular patient. That the patient may define what is in his best interest and that such a declaration should be accepted by surrogate decision-maker is well recognized in many adjudicated cases. (See In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976); Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (Mass. 1977) and Eichner v. Dillon, 426 N.Y.S.2d 517 (1981)).

Personal autonomy is the basis for the concept of the health-care representative in Section 6. Where a person appointing a health-care representative has given particular instructions, those instructions should define the best interest of a patient. If no specific directions are given, the more general best interest standard applies.

If the health-care representative cannot in good conscience follow the directions provided by his appointor he must resign or seek relief from that mandate by a court. The health-care representative

would be an interested individual entitled to petition a court under Section ". In the event the health-care representative does not act, consent must be obtained from one of those individuals authorized in Section 4 to act for the patient or from a court under Section 7.

Section 6 is consistent with the Uniform Durable Power of Attorney Act. The appointment made under this section would be given effect without this Act in a jurisdiction which has enacted the Durable Power of Attorney Act. By incorporating this section into the Act, the power of appointment will be brought to the attention of persons who may not be aware of the Durable Power Act.

Because the power of appointment is unique, the Conference concluded it was desirable to set forth a suggested form instrument to be used for the appointment of a health-care representative.

Appointment of a Health-Care Representative

I, the undersigned, voluntarily appoint

_____

whose telephone number and address are

_____

_____

as my health-care representative who is authorized to act for me in all matters of health care, except as otherwise specified below.

This appointment is subject to the following special provisions:

_____

_____

_____

This appointment (becomes effective) (remains effective) (terminates) if I later become disabled or incapable of consenting to my health care. I (do) (do not) authorize my health-care representative hereby appointed to delegate decision-making power to another.

Dated this _____ day of _____, 19____.

_____

(signed)

_____

(address)

I declare that at the request of the above-named individual making the appointment, I witnessed the signing of this document.

_____

(signed)

_____

(address)

Acceptance by Health-Care Representative

I, the undersigned health-care representative, understand that acceptance of this appointment means that I have a duty to act in good faith and in the best interest of the individual appointing me. I further understand that I have a duty to follow any special instructions in the appointment. In the event I cannot do so, I will exercise no further power under the appointment and will inform (i) the individual appointing me, if that individual is capable of consenting, (ii) his/her legal representative, if known to me, and (iii) his/her health-care provider if known to me.

Dated this _____ day of _____, 19____.

_____

(signed)

_____

(address)

Library References

Mental Health ⟨⟩113, 174.
C.J.S. Insane Persons §§ 37, 40, 47.

§ 7. Court-Ordered Health Care or Court-Ordered Appointment of a Representative

(a) A health-care provider or any interested individual may petition the [_____] court to (i) make a health-care decision or order health-care for an individual incapable of consenting or (ii) appoint a representative to act for that individual.

[(b) Reasonable notice of the time and place of hearing a petition under this section must be given to the individual incapable of consenting and to individuals in the classes described in Section 4 who are reasonably available.

(c) The court may modify or dispense with notice and hearing if it finds that delay will have a serious, adverse effect upon the health of the individual.]

(d) The court may order health care, appoint a representative to make a health-care decision for the individual incapable of consenting to health care with such limitations on the authority of the representative as it considers appropriate, or order any other appropriate relief in the best interest of that individual, if it finds:

(1) a health-care decision is required for the individual;

(2) the individual is incapable of consenting to health care; and

(3) there is no individual authorized to consent or an individual authorized to consent to health care is not reasonably available, declines to act, or is not acting in the best interest of the individual in need of health care.

COMMENT

Section 7 is designed to operate in two basic situations. The first is that in which an individual is in need of health care and incapable of consenting and there is no one to act on his behalf. It is not infrequent that a person admitted to a hospital has no known relatives or friends. The second is that in which one authorized to act is not acting in the best interest of the individual who is incapable of consenting. If the parents of a minor refuse medical treatment because of the parents' religious convictions courts have not hesitated to take the decision-making authority from the parent when the child's life is endangered.[1]

The removal of a parent's power to consent is generally taken pursuant to state child neglect statutes. However, in some instances courts simply assume the decision-making authority under the *parens patriae* doctrine. Section 7 provides for the same kind of relief that is provided in the child neglect statutes. Section 7 provides a certain and expeditious means for removing one authorized to consent who is not acting in the best interest of a patient. The Act does not attempt to define best interest. There is a developing body of law on that question; however, its contours are not yet clear. (See M. Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 27 Stan. L.Rev. 985, 1031–1033 (1975).

Any health-care provider or any individual is given standing to petition for the appointment of a competent representative to consent to the rendition of health care. A court acting pursuant to this section is authorized to order health care or to appoint a competent representative who is authorized to make health-care decisions. This section does not displace any other state procedures designed to accomplish the same result. Because most states have existing mechanisms to address these questions, the purely procedural portions of Section 7, subsections (b) through (d) are bracketed. They may be deleted from the Act without destroying its integrity.

Library References

Mental Health ⟨⟩ 213, 246.
C.J.S. Insane Persons §§ 79, 85.

§ 8. Disqualification of Authorized Individuals

(a) An individual who may consent to health care for himself under Section 2 may disqualify others from consenting to health care for him.

(b) The disqualification must be in writing, signed by the individual, and designate those disqualified.

(c) A health-care provider who knows of a written disqualification may not accept consent to health care from a disqualified individual.

(d) An individual who knows he has been disqualified to consent to health care for another may not act for the other under this [Act].

COMMENT

A full recognition of individual autonomy requires not only that one be authorized to appoint his health-care representative but that he also be authorized to say whom he does not want to act for him. Section 8 permits this disqualification. A patient may not want to go through the formality of appointing a Section 6 health-care representative but may well wish to exclude certain persons from acting on his behalf.

One who is disqualified under Section 8 has no authority to act. However, unless that disqualification is known to a health-care provider, he may nevertheless rely on an authorization from one who is disqualified. (See Section 9.)

[1] On occasion courts have ordered treatment over the parents' objection even though the proposed treatment was not necessary to save the child's life but posed substantial risks and was not certain to cure the condition. (See In re Sampson, 317 N.Y.S.2d 641 (1970) affirmed 29 N.Y.2d 900, 328 N.Y.S.2d 686 (1972).) In Sampson the minor suffered from a massive overgrowth of facial tissue causing a severe deformity on the right side of his face and neck. The need for treatment was shown by testimony that he did not attend school and suffered a severe learning disability relating to the deformity. The court concluded that the disfigurement so limited the child's development that it had to assume responsibility and order the surgery, even though the procedure entailed obvious risks. (For a contrary result, see In re Seiferth, 309 N.Y. 80, 127 N.E.2d 820 (1955).)

Library References

Mental Health ⟹116.
C.J.S. Insane Persons §§ 42, 43.

§ 9. Limitations of Liability

(a) A health-care provider acting or declining to act in reliance on the consent or refusal of consent of an individual whom he believes in good faith is authorized by this [Act] or other law of this State to consent to health care is not subject to criminal prosecution, civil liability, or professional disciplinary action on the ground that the individual who consented or refused to consent lacked authority or capacity.

(b) A health-care provider who believes in good faith an individual is incapable of consenting under Section 5 is not subject to criminal prosecution, civil liability, or professional disciplinary action for failing to follow that individual's direction.

(c) A person who in good faith believes he is authorized to consent or refuse to consent to health care for another under this [Act] or other law of this State is not subject to criminal prosecution or civil liability on the ground he lacked authority to consent.

COMMENT

Under Section 9, the health-care provider is permitted to rely on the consent of an individual whom he believes in good faith is authorized to consent to health care. In meeting this standard under the Act, a health-care provider could not close his eyes to the truth, of course, but to prescribe an affirmative requirement of detailed investigation would make reliance impossible.

Similarly, a health-care provider who makes a determination that one is incapable of consenting and thus calls in a third-party decision-maker is not subject to liability for discharging his obligation in good faith.

An individual acting for another is in every sense of the word a fiduciary and has those obligations which a fiduciary owes his ward. The immunity provided in this section does not protect a substitute decision-maker from negligence or other breach of duty but only from acting without authority if he in good faith believes that he is authorized to give consent.

Library References

Mental Health ⟹179.
C.J.S. Insane Persons §§ 49.

§ 10. Availability of Medical Information

An individual authorized to consent to health care for another under this [Act] has the same right as does the individual for whom he is acting to receive information relevant to the contemplated health care and to consent to the disclosure of medical records to a contemplated health-care provider. [Disclosure of information regarding contemplated health care to an individual authorized to consent for another is not a waiver of an evidentiary privilege.]

COMMENT

An individual authorized to consent for another stands in the shoes of the patient when making health-care decisions. The individual authorized to consent is entitled to receive information relevant to the proposed health care whether or not that is allowable under any other provision of state law. This section guarantees that right but makes no attempt to define the scope of disclosure required.[1]

In many cases, proper diagnosis and treatment require that medical information must be passed from one doctor or hospital to another. Because of the confidential or privileged nature of much of this information, the patient's consent is necessary before the information can be disclosed. (61 Am.Jur.2d Physicians & Surgeons § 101 (1972) and 20 A.L.R.3d 1109 (1968).) To the extent that the patient has a right which can be waived, an individual acting on his behalf has the same right of waiver. The Act does not determine whether confidential information or a privilege exists in the first instance.

Library References

Physicians and Surgeons ⟹15(8).
Witnesses ⟹208(1).
C.J.S. Physicians and Surgeons § 48.
C.J.S. Witnesses §§ 293, 312.

§ 11. Effect on Existing State Law

(a) This [Act] does not affect the law of this State concerning an individual's authorization to make a health-care decision for himself or another to withdraw or withhold medical care necessary to preserve or sustain life.

[1] For a detailed bibliography of informed consent see A. Meisel, The Expansion of Liability for Medical Accidents: From Negligence to Strict Liability By Way of Informed Consent, 56 Neb.L.Rev. 51, 75 n. 64 (1977) and A. Meisel, The Exceptions to the Informed Consent Doctrine: Striking A Balance Between Competing Values in Medical Decisionmaking, 1979 Wis.L.Rev. 413 n. 3.

(b) This [Act] does not affect the requirements of any other law of this State concerning consent to observation, diagnosis, treatment, or hospitalization for a mental illness.

(c) This [Act] does not authorize an individual to consent to any health care prohibited by the law of this State.

(d) This [Act] does not affect any requirement of notice to others of proposed health care under any other law of this State.

(e) This [Act] does not affect the law of this State concerning (i) the standard of care of a health-care provider required in the administration of health care, (ii) when consent is required for health care, (iii) informed consent for health care, or (iv) consent to health care in an emergency.

(f) This [Act] does not prevent an individual capable of consenting to health care for himself or another under this [Act], including those authorized under Sections 4, 5 and 6, from consenting to health care administered in good faith pursuant to religious tenets of the individual requiring health care.

COMMENT

Section 11 contains important limitations. It is written to make clear that this Act does not intrude into areas of the law where its operation would be inappropriate.

The law with respect to the withdrawal of life support systems in the case of the terminally ill is changing rapidly. At least 10 states have Natural Death Acts and there have been several court decisions concerning the issue of termination of treatment. Nothing in this Act changes existing law in that regard. All proxy decisionmakers are charged with acting in the best interest of the patient who is incapable of consenting. If a patient had appointed a health-care representative and had made known his wish that life support systems are withdrawn in the event of terminal illness, many courts would consider that evidence conclusive of the patient's best interest. However, this Act does not provide an answer to the question of what is in the patient's best interest in such a circumstance.

Subsection (b) provides that the Act will not override the operation of mental health codes. All states require that commitment proceedings be surrounded with stringent procedural safeguards which must be adhered to before an individual can be involuntarily committed. Subsection (b) makes it clear that this Act does not allow any individual authorized to consent for another to bypass those commitment statutes under the guise of a voluntary commitment. In addition, subsection (b) prohibits this Act from being used to authorize forcible drug medication unless in conformity with other proper procedural requirements.

Subsection (c) is written to make it clear that this Act does not authorize one to consent to medical procedures which are prohibited by law.

The Supreme Court has held in Belloti v. Baird, 443 U.S. 622 (1979) that minors are entitled to consent to an abortion without parental consent. That holding is recognized in Section 2 which permits minors to consent to health care which is otherwise authorized by law. However, the Supreme Court held in the case of H. L. v. Matheson, 450 U.S. 398, 101 S.Ct. 1164 (1981) that a state requirement of notice to parents does not violate the constitutional rights of a minor. Subsection (d) is written to ensure that state statutes, such as the Utah statute under review in **Matheson**, are not affected by this Act.

This Act is narrow in scope. It is not concerned with the standard of care required of health-care providers. It is not concerned with whether, how and under what circumstances consent to health care is required. Nor is it an informed consent statute. As outlined in the Prefatory Note, this statute is basically a procedural one and matters of state substantive law are unchanged.

Section 2 of this Act limits health-care providers to those who are licensed, certified or otherwise authorized to provide health care. Practitioners of religious healing, for instance, Christian Science Practitioners are not licensed, certified or authorized by the state but practice as matter of the free exercise of religion. Yet spiritual healing is a well recognized form of health care and there is no intention to make this religious activity illegal by the operation of this Act. There is no intention to prevent an individual capable of consenting to health care from consenting for another or himself to spiritual healing which is health care administered in good faith pursuant to religious tenets of the individual requiring health care as a matter of free exercise of religion. Certainly those practitioners of religious healing should not be required to seek state authorization to practice their faith. Hence, subsection (f) is an express savings clause to permit one to consent to spiritual healing as health care.

Library References

Assault and Battery ⟨⟩ 2, 11.
Physicians and Surgeons ⟨⟩ 15(8).
C.J.S. Assault and Battery §§ 2 to 4, 6 to 8, 16, 17.
C.J.S. Physicians and Surgeons § 48.

§ 12. Severability

If any provisions of this [Act] or the application hereof to any person or circumstance is held invalid, the invalidity does not affect other provisions or applications of the [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

Library References

Statutes ⟨⟩ 64(1).
C.J.S. Statutes § 92 et seq.

§ 13. Uniformity of Application and Construction

This [Act] shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this [Act] among states enacting it.

Library References

C.J.S. Statutes § 388.
Statutes ⟨⟩ 236.

§ 14. Short Title

This [Act] may be cited as the Uniform Law Commissioners' Model Health-Care Consent Act.

§ 15. Repeal

The following acts and parts of acts are repealed:
(1)
(2)
(3)

§ 16. Time of Taking Effect

This [Act] shall take effect

APPENDIX G

UNIFORM RIGHTS OF THE TERMINALLY ILL ACT

Drafted by the

NATIONAL CONFERENCE OF COMMISSIONERS
ON UNIFORM STATE LAWS

and by it

Approved and Recommended for Enactment
in All the States

At Its

ANNUAL CONFERENCE
MEETING IN ITS NINETY-FOURTH YEAR
IN MINNEAPOLIS, MINNESOTA
AUGUST 2–9, 1985

With Prefatory Note and Comments

UNIFORM RIGHTS OF THE TERMINALLY ILL ACT

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PREFATORY NOTE

The Rights of the Terminally Ill Act authorizes an adult person to control decisions regarding administration of life-sustaining treatment by executing a declaration instructing a physician to withhold or withdraw life-sustaining treatment in the event the person is in a terminal condition and is unable to participate in medical treatment decisions. As the preceding sentence indicates, the scope of the Act is narrow. It does not address treatment of persons who have not executed such a declaration; it does not cover treatment of minors; and it does not address treatment decisions by proxy. Its impact is limited to treatment that is merely life prolonging, and to patients whose terminal condition is incurable and/or irreversible, whose death will soon occur, and who are unable to participate in treatment decisions. Beyond its narrow scope, the Act is not intended to affect any existing rights and responsibilities of persons to make medical treatment decisions. The Act merely provides **one** way by which a terminally-ill patient's desires regarding the use of life-sustaining procedures can be legally implemented.

The purposes of the Act are (1) to present an Act which is simple, effective, and acceptable to persons desiring to execute a declaration and to physicians and health-care facilities whose conduct will be affected, (2) to provide for the effectiveness of a declaration in states other than the state in which it is executed through uniformity of scope and procedure, and (3) to avoid the inconsistency in approach which has characterized the early statutes.

The Act's basic structure and substance are similar to that found in most of the existing legislation. The Act has drawn upon existing legislation in order to avoid further complexity and to permit its effective operation in light of prior enactments. Departures from existing statutes have been made, however, in order to simplify procedures, improve drafting, and clarify language. Selected provisions have been reworked to express more adequately a specific concept (i.e., life-sustaining treatment, terminal condition), or to reflect changes in established procedure (i.e., the qualifications of witnesses). The Act's stylistic and substantive departures from existing legislation were pursued for the purposes of clarity and simplicity.

§ 1. Definitions

As used in this [Act], unless the context otherwise requires:

(1) "Attending physician" means the physician who has primary responsibility for the treatment and care of the patient.

(2) "Declaration" means a writing executed in accordance with the requirements of Section 2(a).

(3) "Health-care provider" means a person who is licensed, certified, or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

(4) "Life-sustaining treatment" means any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the process of dying.

(5) "Person" means an individual, corporation, business trust, estate, trust, partnership, association, joint venture, government, governmental subdivision or agency, or any other legal or commercial entity.

(6) "Physician" means an individual [licensed to prctice medicine in this State].

(7) "Qualified patient" means a patient [18] or more years of age who has executed a declaration and who has been determined by the attending physician to be in a terminal condition.

(8) "State" means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

(9) "Terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time.

COMMENT

The Act's definitions of "life-sustaining treatment" and "terminal condition" are interdependent and must be read together. This has caused drafting problems in many existing acts, and the Act has been drafted to avoid the problems detected in existing legislation.

Most of the "life-sustaining treatment" and "terminal condition" definitions in existing statutes were considered problematical in that they (1) were tautological, defining "terminal condition" with respect to "life-sustaining treatment" and vice versa, and (2) defined terminal condition as requiring "imminent" death "whether or not" or "regardless of" the application of life-sustaining treatment. Strictly speaking, if death is "imminent" even with the full application of life-sustaining treatment, there is little point in having a statute permitting withdrawal of such procedures. The Act's definitions have attempted to avoid these problems.

The "life-sustaining treatment" definition found in many statutes inserts the clause "and when, in the judgment of the attending physician, death will occur whether or not such procedure or intervention is utilized," after the phrase "will serve only to prolong the dying process" found in the Act's provision. Because the Act's life-sustaining treatment definition concerns only those procedures or interventions applied to "qualified patients" (i.e., those who have been determined to be in a terminal condition), and because a terminal condition is defined as "incurble or irreversible" with death resulting "in a relatively short time," the requirement that death be "inevitable" has been satisfied by the presence of "qualified patient" in the life-sustaining treatment definition. Therefore, this additional clause was excluded because it was considered repetitious and possibly confusing.

The Act defines "life-sustaining treatment" in an all-inclusive manner, dealing with those procedures necessary for comfort care or alleviation of pain separately in Section 6(b), where it is provided that such procedures need not be withdrawn or withheld pursuant to a declaration. Most existing statutes incorporate "comfort care" as an exclusion from the definition of life-sustaining treatment. Because many such procedures are life-sustaining, however, the Act avoids definitional confusion by treating them in a separate provision that reflects the Act's policy more clearly, and better reflects the fact that comfort care does not involve a fixed group of procedures applicable in all instances.

Subsection (9) of Section 1 is the "terminal condition" definition. The difficulty of trying to express such a condition in precise, accurate, but not unduly restricting language is obvious. A definition must preserve the physicians' professional discretion in making such determinations. Consequently, the Act's definition of terminal condition incorporates not only selected language from various state acts, but also suggestions from medical literature in the field.

The Act employs the term "terminal condition" rather than terminal illness, and it is important that these two different concepts be distinguished. Terminal illness, as generally understood, is both broader and narrower than terminal condition. Terminal illness connotes a disease process that will lead to death; "Terminal condition" is not limited to disease. "terminal illness" also connotes an inevitable process leading to death, but does not contain limitations as to the time period prior to death, or potential for nonreversibility, as does "terminal condition."

The terminal condition definition requires that the condition be "incurable or irreversible." These adjectives were chosen over the similar phrase, "no possibility of recovery," because of possible ambiguity in the term "recovery" (i.e., recovery to "normal" or to some other stage). A number of state statutes now use "incurable" and/or "irreversible," and the terms appear to comport with the criteria applied by physicians in terminal care situations. The phrase "incurable or irreversible" to to be read conjunctively when the circumstances warrant. A condition which is reversible but incurable is not a terminal condition.

Subsection (9) also requires that the condition result in the death of the patient within a "relatively short time . . . without the administration of life-sustaining treatment." This requirement differs to some degree from the language employed in most of the statutes. First, the decision that death will occur in a relatively short time is to be made without considering the possibilities of extending life with life-sustaining treatment. The alternative is that required by a number of states—that death be imminent whether or not life-sustaining procedures are applied. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research has noted that such a definition severely limits the group of terminally-ill patients able to qualify under these acts. It is precisely because life can be prolonged indefinitely by new medical technology that these acts have come into existence. Though the Act intends to err on the side of prolonging life, it should not be made wholly ineffective as to the actual situation it purports to address. The provisions which require that death be imminent regardless of the application of life-sustaining procedures appear to have that effect. Therefore, such provisions have been excluded in the Act.

The terminal condition definition of subsection (9) requires that death result "in a relatively short time." Rejecting the "imminency" language employed in a number of statutes, this alternative was chosen because it provides needed flexibility and reflects the balancing character of the time frame judgment. Though the phrase, "relatively short time" does not eliminate the need for judgment, it focuses the physician's medical judgment and avoids the narrowing implications of the word "imminent."

The "relatively short time" formulation is employed to avoid both the unduly constricting meaning of "imminent" and the artificiality of another alternative—fixed time periods, such as six months, one year, or the like. The circumstances and in-

evitable variations in disorder and diagnosis make unrealistic a fixed time period. Physicians may be hesitant to make predictions under a fixed time period standard unless the standard of physician judgment is so loose as to be unenforceable. Under the Act's standard, considerations such as the strength of the diagnosis, the type of disorder, and the like can be reflected in the judgment that death will result within a relatively short time, as they are now reflected in judgments physicians must and do make.

The life-sustaining treatment and terminal condition definitions exclude certain types of disorders, such as kidney disease requiring dialysis, and diabetes requiring continued use of insulin. This is accomplished in the requirement that terminal conditions be "irreversible," and that life-sustaining procedures serve "**only** to prolong the dying process." For purposes of the Act, diabetes treatable with insulin is "reversible," a diabetic person so treatable is not in the "dying process," and insulin is a treatment the benefits of which foreclose it serving "**only**" to prolong the dying process.

§ 2. Declaration Relating to Use of Life-Sustaining Treatment

(a) An individual of sound mind and [18] or more years of age may execute at any time a declaration governing the withholding or withdrawal of life-sustaining treatment. The declaration must be signed by the declarant, or another at the declarant's direction, and witnessed by two individuals.

(b) A declaration may, but need not, be in the following form:

Declaration

If I should have an incurable or irreversible condition that will cause my death within a relatively short time, and I am no longer able to make decisions regarding my medical treatment, I direct my attending physician, pursuant to the Uniform Rights of the Terminally Ill Act of this State, to withhold or withdraw treatment that only prolongs the process of dying and is not necessary to my comfort or to alleviate pain.

Signed this _____ day of _____

_____
Signature

_____
Address

The declarant voluntarily signed this writing in my presence.

_____
Witness

_____
Address

_____
Witness

_____
Address

(c) A physician or other health-care provider who is furnished a copy of the declaration shall make it a part of the declarant's medical record and, if unwilling to comply with the declaration, promptly so advise the declarant.

COMMENT

Section 2 sets out the minimal requirements regarding the making and execution of a valid declaration. A "sample" declaration form is offered in this section. The form is not mandatory, as some acts require; it "may, but need not, be" followed. The form provided also is not as elaborate as others. The drafters rejected a more detailed declaration for two reasons. First, the form is to serve only as an example of a valid declaration. A more elaborate form may have erroneously implied that a declaration more simply constructed would not be legally sufficient. Second, the sample form's simple structure and specific language attempts to provide notice of exactly what is to be effectuated through these documents to those persons desiring to execute a declaration and the physicians who are to honor it.

The Act's provisions governing witnesses to a declaration have also been simplified. Section 2 provides only that the declaration be signed by the declarant in the presence of two witnesses. The Act does not require witnesses to meet any specific qualifications for two primary reasons. First, the interest in simplicity mandates as uncomplicated a procedure as possible. It is intended that the Act present a viable alternative for those persons interested in participating in their medical treatment decisions in the event of a terminal condition.

Second, the absence of more elaborate witness requirements relieves physicians of the inappropriate and perhaps impossible burden of determining whether the legalities of the witness requirements have been met. Many physicians understandably and rightly would be hesitant to make such decisions and, therefore, the effectiveness of the declaration

might be jeopardized. It should be noted, as well, that protection against abuse in these situations is provided by the criminal penalties in Section 9. The attending physicians and other health-care professionals will be able, in most circumstances, to discuss the declaration with the patient and family and any suspicion of duress or wrongdoing can be discovered and handled by established hospital procedures.

Section 2(c) requires that a physician or health-care provider who is given a copy of the declaration record it in the declarant's medical records. This step is critical to the effectuation of the declaration, and the duty applies regardless of the time of receipt. If a copy of the same declaration is already in the record, its rerecording would not be necessary, but its receipt should be noted as evidence of its continued force. Section 2(c) is not duplicative of Section 5 which requires recording the terms of the declaration (or the document itself, when available, in the event of telephonic communication to the physician by another physician, for example) at the time the physician makes a determination of terminal condition. It was deemed important that knowledge of the declaration and its continued force be specifically noted at this critical juncture.

Section 2(c) imposes a duty on the physician or other health-care provider to inform the declarant of his or her unwillingness to comply with the provisions of the declaration. This will provide notice to the declarant that certain terms may be deemed medically unreasonable (Section 10(f)), or that a different provider who is willing to carry out the Act (Section 7) should be informed of the declaration.

§ 3. When Declaration Operative

A declaration becomes operative when (i) it is communicated to the attending physician and (ii) the declarant is determined by the attending physician to be in a terminal condition and no longer able to make decisions regarding administration of life-sustaining treatment. When the declaration becomes operative, the attending physician and other health-care providers shall act in accordance with its provisions or comply with the transfer provisions of Section 7.

COMMENT

Section 3 established the preconditions to the declaration becoming operative. Once operative, Section 3 provides that the attending physician shall act in accordance with the provisions of the declaration or transfer care of the patient under Section 7. This provision is not intended to eliminate the physician's need to evaluate particular requests in terms of reasonable medical practice under Section 10(f), nor to relieve the physician from carrying out the declaration except for any specific unreasonable or unlawful request in the declaration. Transfer of the patient under Section 7 is to occur if the physician, for reasons of conscience, for example, is unwilling to carry ouf the Act or to follow medically reasonable requests in the declaration.

§ 4. Revocation of Declaration

(a) A declaration may be revoked at any time and in any manner by the declarant, without regard to the declarant's mental or physical condition. A revocation is effective upon communication to the attending physician or other health-care provider by the declarant or a witness to the revocation.

(b) The attending physician or other health-care provider shall make the revocation a part of the declarant's medical record.

COMMENT

Section 4 provides for revocation of a declaration and is modeled after North Carolina's similar provision. Virtually every other statute sets out specific examples of how a declaration can be revoked—by physical destruction, by a signed, dated writing, or by a verbal expression of revocation. A provision that freely allowed revocation and avoided procedural complications was desired. The simple language of Section 4 appears to meet these qualifications. It should be noted that the revocation is, of course, not effective until communicated to the attending physician or another health-care provider working undr a physician's guidance, such as nursing facility or hospice staff. The Act, unlike many statutes, also does not explicitly require that a person relaying the recovation be acting on the declarant's behalf. Such a requirement could impose an unreasonable burden on the attending physician. The communication is assumed to be in good faith, and the physician may rely on it.

In employing a general revocation provision, it was intended to permit revocation by the broadest range of means. Therefore, for example, it is intended that a revocation can be effected in writing, orally, by physical defacement or destruction of a declaration, and by physical sign communicating intention to revoke.

§ 5. Recording Determination of Terminal Condition and Declaration

Upon determining that the declarant is in a terminal condition, the attending physician who knows

of a declaration shall record the determination and the terms of the declaration in the declarant's medical record.

COMMENT

Section 5 of the Act requires that an attending physician record the determination that the patient is in a terminal condition in the patient's medical records. The section provides that an attending physician must know of the declaration's existence. It is anticipated that knowledge may in some instances occur through oral communication between physicians. If the attending physician determines that the patient is in a terminal condition, and has been notified of the declaration, the physician is to make the determination of terminal condition, as defined in Section 1(8), part of the patient's medical records. There is no explicit requirement that the physician inform the patient of the terminal condition. That decision is to be left to the physician's professional discretion under existing standards of care. The Act also does not require, as do many statutes, that a physician other than the attending physician concur in the terminal condition determination. It appears to be the established practice of most physicians to request a second opinion or, more often, review by a panel or committee established as a matter of hospital procedure, and the Act is not intended to discourage such a practice. Requiring it, however, would almost inevitably freeze in a single process or set of processes for review in this evolving area of medicine. Because existing policies and regulations typically address the review issue, requiring a specific form of review in the Act was viewed as an unnecessary regulation of normal hospital procedures. Moreover, in smaller or rural health facilities a second qualified physician or review mechanism may not be readily available to confirm the attending physician's determination.

The physician must record the terms of the declaration in the medical record so that its specific language or any special provisions are known at later stages of treatment. It is assumed that "terms" of the declaration will be a copy of the declaration itself in most instances, although cases of an emergency character may arise, for example, in which the contents of a declaration can be reliably conveyed, and where obtaining a copy of the declaration prior to making decisions governed by it will be impracticable. In such cases, the terms of the declaration will suffice for recording purposes under Section 5.

§ 6. Treatment of Qualified Patient

(a) A qualified patient may make decisions regarding life-sustaining treatment as long as the patient is able to do so.

(b) This [Act] does not affect the responsibility of the attending physician or other health-care provider to provide treatment, including nutrition and hydration, for a patient's comfort care or alleviation of pain.

(c) Unless the declaration otherwise provides, the declaration of a qualified patient known to the attending physician to be pregnant must not be given effect as long as it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining treatment.

COMMENT

Section 6(a) recognizes the right of patients who have made a declaration and are determined to be in a terminal condition to make decisions regarding use of life-sustaining procedures. Until unable to do so, such patients have the right to make such decisions independently of the terms of the declaration. In affording patients a "right to make decisions regarding use of life-sustaining procedures," the Act is intended to reflect existing law pertaining to this issue. As Sections 10(e) and (f) indicate, qualifications on a patient's right to force the carrying out of those decisions in a manner contrary to law or accepted standards of medical practice, for example, are not intended to be overridden.

In Section 6(b) the Act uses the term "comfort care" in defining procedures that may be applied notwithstanding a declaration instructing withdrawal or withholding of life-sustaining treatment. The purpose for permitting continuation of life-sustaining treatment deemed necessary for comfort care or alleviation of pain is to allow the physician to take appropriate steps to insure comfort and freedom from pain, as dictated by reasonable medical standards. Many existing statutes employ the term "comfort care" in connection with the alleviation of pain, and the Act follows this example. Although the phrase "to alleviate pain" arguably is subsumed within the term comfort care, the additional specificity was considered helpful for both the doctor and layperson.

Section 6(b) does not set out a separate rule governing the provision of nutrition and hydration. Instead, each is subject to the same considerations of

necessity for comfort care and alleviation of pain as are all other forms of life-sustaining treatment. If nutrition and hydration are not necessary for comfort care or alleviation of pain, they may be withdrawn. This approach was deemed preferable to the approach in a few existing statutes, which treat nutrition and hydration as comfort care in all cases, regardless of circumstances, and exclude comfort care from the life-sustaining treatment definition.

It is debatable whether physicians or other professionals perceive the providing of nourishment through intravenous feeding apparatus or nasogastric tubes as comfort care **in all cases** or whether such procedures at times merely prolong the dying process. Whether procedures to provide nourishment should be considered life-sustaining treatment or comfort care appears to depend on the factual circumstances of each case and, therefore, such decisions should be left to the physician, exercising reasonable medical judgment. Declarants may, however, specifically express their views regarding continuation or noncontinuation of such procedures in the declaration, and those views will control.

Section 6(c) addresses the problem of a qualified patient who is pregnant. The states which address this issue typically require that the declaration be given no force or effect during the pregnancy. Because this requirement inadvertently may do more harm than good to the fetus, Section 6(c) provides a more suitable, if more complicated, standard. It is possible to hypothesize a situation in which life-sustaining treatment, such as medication, may prove possibly fatal to a fetus which is at or near the point of viability outside the womb. In such cases, the Act's provision would permit the life-sustaining treatment to be withdrawn or withheld as appropriate in order best to assure survival of the fetus. Also, for example, if the qualified patient is only a few weeks pregnant and the physician, pursuant to reasonable medical judgment, determines that it is not probable that the fetus could develop to a point of viability outside the womb even with the application of life-sustaining treatment, such treatment may also be withheld or withdrawn. Thus, the pregnancy provision attempts to honor the terminally-ill patient's right to refuse life-sustaining treatment without jeopardizing in any respect the likelihood of life for the fetus. The declaration can, however, specifically address this issue, and should control the treatment provided, whether it calls for continuation of life-sustaining treatment in all cases, or in none.

§ 7. Transfer of Patients

An attending physician or other health-care provider who is unwilling to comply with this [Act] shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider.

COMMENT

Section 7 is designed to address situations in which a physician or health-care provider is unwilling to make and record a determination of terminal condition, or to respect the medically reasonable decisions of the patient regarding withholding or withdrawal of life-sustaining procedures, due to personal convictions or policies unrelated to medical judgment called for under the Act. In such instances, the physician or health-care provider must promptly take all reasonable steps to transfer the patient to another physician or health-care provider who will comply with the applicable provisions of the Act.

§ 8. Immunities

(a) In the absence of knowledge of the revocation of a declaration, a person is not subject to civil or criminal liability or discipline for unprofessional conduct for carrying out the declaration pursuant to the requirements of this [Act].

(b) A physician or other health-care provider, whose actions under this [Act] are in accord with reasonable medical standards, is not subject to criminal or civil liability or discipline for unprofessional conduct with respect to those actions.

COMMENT

Section 8 provides immunities for persons acting pursuant to the declaration and in accordance with the Act. Immunities are extended in Section 8(a) to physicians as well as persons operating under the physician's direction or with the physician's authorization, and to facilities in which the withholding or withdrawal of life-sustaining procedures occurs. Section 8(b) serves both to immunize physicians from liability as long as reasonable medical judgment is exercised, and to impose "reasonable medical standards" as the criterion that should govern all of the specific medical decisions called for throughout the Act. Section 8(b), in conjunction with Section 10(f), therefore, avoids the need to restate the medical standard in each section of the Act requiring a medical judgment.

§ 9. Penalties

(a) A physician or other health-care provider who willfully fails to transfer in accordance with Section 7 is guilty of [a class ____ misdemeanor]

(b) A physician who willfully fails to record the determination of terminal condition in accordance with Section 5 is guilty of [a class ____ misdemeanor]

(c) An individual who willfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another is guilty of [a class ____ misdemeanor]

(d) An individual who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 4, is guilty of [a class ____ misdemeanor]

(e) A person who requires or prohibits the execution of a declaration as a condition for being insured for, or receiving, health-care services is guilty of [a class ____ misdemeanor]

(f) A person who coerces or fraudulently induces another to execute a declaration under this [Act] is guilty of [a class ____ misdemeanor]

(g) The sanctions provided in this section do not displace any sanction applicable under other law.

COMMENT

Section 9 provides criminal penalties for specific conduct that violates the Act. Subsections (a) and (b) provide that a physician's failure to transfer a patient or record the diagnosis of terminal condition constitutes a misdemeanor. Subsection (c) makes certain willful actions which could result in the unauthorized prolongation of life a misdemeanor. Subsection (d) governs acts which are intended to cause the unauthorized withholding or withdrawal of life-sustaining treatment, thereby advancing death. Subsections (e) and (f) concern situations that may be coercive, and therefore are against public policy.

Some of the criminal penalties—particularly subsection (d)—depart significantly from most existing statutes. Most statutes provide penalties for intentional conduct that actually causes the death of a declarant, and define such conduct as murder or a high degree felony. The Act does not take this approach. Assuming that such conduct will already be covered by a state's criminal statutes, the Act only addresses the situations in which the actor willfully falsifies or forges the declaration of another or conceals or withholds knowledge of revocation. To be criminally sanctioned as a misdemeanor under the Act the circumscribed conduct need not cause the death of a declarant. The approach taken by most states, that of providing a felony penalty for those acts that actually caused death, was considered unnecessary, as existing criminal law will also apply pursuant to Section 9(g). A specific penalty for the conduct described in Section 9(d), however, was deemed appropriate, as existing criminal codes may not adequately address it.

§ 10. Miscellaneous Provisions

(a) Death resulting from the withholding or withdrawal of life-sustaining treatment pursuant to a declaration and in accordance with this [Act] does not constitute, for any purpose a suicide or homicide.

(b) The making of a declaration pursuant to Section 2 does not affect in any manner the sale, procurement, or issuance of any policy of life insurance or annuity, nor does it affect, impair, or modify the terms of an existing policy of life insurance or annuity. A policy of life insurance or annuity is not legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining treatment from an insured qualified patient, notwithstanding any term to the contrary.

(c) A person may not prohibit or require the execution of a declaration as a condition for being insured for, or receiving, health-care services.

(d) This [Act] creates no presumption concerning the intention of an individual who has revoked or has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining treatment in the event of a terminal condition.

(e) This [Act] does not affect the right of a patient to make decisions regarding use of life-sustaining treatment, so long as the patient is able to do so, or impair or supersede any right or responsibility that a person has to effect the withholding or withdrawal of medical care.

(f) This [Act] does not require any physician or other health-care provider to take any action contrary to reasonable medical standards.

(g) This [Act] does not condone, authorize, or approve mercy-killing or euthanasia.

§ 11. When Health-Care Provider May Presume Validity of Declaration

In the absence of knowledge to the contrary, a physician or other health-care provider may presume that a declaration complies with this [Act] and is valid.

§ 12. Recognition of Declaration Executed in Another State

A declaration executed in another state in com-

pliance with the law of that state or of this State is validly executed for purposes of this [Act].

COMMENT

Section 12 provides that a declaration executed in another state, which meets the *execution* requirements of that other state or the enacting state (adult, two witnesses, voluntary), is to be treated as validly *executed* in the enacting state, but its operation in the enacting state shall be subject to the substantive policies in the enacting state's law.

§ 13. Effect of Previous Declaration

An instrument executed before the effective date of this [Act] which substantially complies with Section 2(a) must be given effect pursuant to the provisions of this [Act].

§ 14. Uniformity of Construction and Application

This [Act] shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this [Act] among states enacting it.

§ 15. Short Title

This [Act] may be cited as the Uniform Rights of the Terminally Ill Act.

§ 16. Severability

If any provision of this [Act] or its application to any person or circumstance is held invalid, the invalidity does not affect other provisions or applications of this [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

§ 17. Effective Date

This [Act] takes effect on _____.

§ 18. Repeal

The following acts and parts of acts are repealed:

(1)

(2)

(3)

APPENDIX H

AMERICAN MEDICAL ASSOCIATION STATEMENT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

March 15, 1986

Withholding or Withdrawing Life Prolonging Medical Treatment

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail. In the absence of the patient's choice or an authorized proxy, the physician must act in the best interest of the patient.

For humane reasons, with informed consent, a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to permit a terminally ill patient whose death is imminent to die. However, he should not intentionally cause death. In deciding whether the administration of potentially life-prolonging medical treatment is in the best interest of the patient who is incompetent to act in his own behalf, the physician should determine what the possibility is for extending life under humane and comfortable conditions and what are the prior expressed wishes of the patient and attitudes of the family or those who have responsibility for the custody of the patient.

Even if death is not imminent but a patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis and with the concurrence of those who have responsibility for the care of the patient, it is not unethical to discontinue all means of life prolonging medical treatment.

Life prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained.

APPENDIX I

VIEWS OF THE AMERICAN HEALTH CARE ASSOCIATION

HEALTH CARE DECISIONMAKING IN LONG TERM CARE FACILITIES

The American Health Care Association (AHCA), representing over 8,000 nursing homes caring for more than 800,000 infirm elderly, convalescent and chronically ill individuals of all ages, has developed this policy on health care decisionmaking in order to state its position on these issues, raise questions of public policy and provide guidance to state affiliates and member facilities.

This policy makes recommendations for consideration by state affiliates and individual facilities. However, because of wide differences in state law and the rapidly changing state of the law within jurisdictions, it does not attempt to provide specific guidance and should be considered only as a starting point in the development of specific policies and procedures.

Introduction

Health care treatment decisions, frequently with life and death implications, are made in long term care facilities on a daily basis. The American Health Care Association (AHCA) believes that the issues and problems accompanying the decisionmaking process are too important to be ignored; they must be discussed and resolved openly. Realizing that these issues should most appropriately be resolved at the state level, AHCA has developed this policy to assist its state affiliates and member facilities in developing their own policies and promoting resolution of these issues. In this statement, AHCA highlights legal and public policy issues which must be considered, and discusses specific procedural matters that should be addressed in facility policies and procedures. AHCA believes that state laws addressing these issues should specify decisionmaking procedures and identify, in broad terms, circumstances in which such procedures may be used. Such laws should not, however, attempt to define the precise conditions (such as "when death is imminent" or "in a persistent vegetative state") when the specified procedures may be used.

Facility policies and procedures should provide for prompt, orderly and informed decisionmaking. Among other things, they should recognize residents' competence, provide efficiently and appropriately for opportunities to designate surrogates, ensure that residents are adequately informed and their rights are protected and where appropriate, provide for review of decisionmaking. Procedures must also ensure adequate documentation throughout the process.

The role of state affiliates will vary. In some cases, they may play a primary role in facilitating public discussion and presenting issues to state legislators and administrative officials. In others, they may choose to coordinate the development of policies and procedures that can be adopted by individual facilities. While recognizing the importance of the state affiliate's role, this document focuses on facility policies and procedures, for it is the individual facility that is directly involved in and potentially responsible for the ways in which health care decisions are made by and for its residents.

In developing policies and procedures, state affiliates and individual facilities should also consider state statutory and case law, ethical codes and practice rules for the professionals involved in the decisionmaking process, the impact of residents' religious beliefs and, of course, in religiously affiliated facilities, the tenets of the applicable religious organization. Specific facility or corporate priorities and policies should also be considered, as well as the advice of legal counsel knowledgeable about health care issues.

I. Overview

A. Public Concern

Recently, public interest in and concern about health care treatment decisions, especially those with immediate life and death implications, have increased markedly. Coverage in the media has included reporting of judicial decisions and interviews with an assortment of legal, medical and ethical authorities. Additionally, numerous treatises and other scholarly works have addressed the significant legal and moral aspects of the issue.

Part of the reason for increased public concern in this area is that medical technology has made it possible to sustain life in circumstances that would have been incomprehensible even ten years ago. As a result, society is now asking whether it is always neces-

sary to do all that is technologically possible to sustain life, and, if not, who has authority to make decisions, what criteria should be applied, and what processes should be used. These questions apply to a wide variety of circumstances involving severely handicapped newborns, apparently healthy adults who suffer cardiac arrest or accidental brain injury, and elderly, severely debilitated individuals with multiple illnesses and other problems.

Many long term care facility residents fall into the last category. The average resident is 84 years old, has multiple diagnoses, and requires assistance in three or more activities of daily living. Approximately 50 percent also suffer from some degree of impairment of their mental or decisionmaking capacities. Many have outlived family or close friends who might otherwise participate or assist in making health care decisions. These factors not only require that the policies and procedures for decisionmaking in long term care facilities be somewhat different from those used in other settings, but they render all the more critical the need for such policies and procedures.

B. Provider Roles

Although health care decisionmaking traditionally has been viewed as the responsibility of physicians, there has been an increasing use of a "team" approach, aimed toward collaboration with patients themselves. Without displacing the continuing need for compassionate, professional judgments by physicians, long term care facilities and their staffs have important responsibilities in facilitating and, where necessary, participating in sound, informed decisionmaking with residents, their families, friends and guardians. Although no staff member should be permitted to assume responsibility for individual decisions, the important role often played by staff should be recognized in facility policies and procedures.

In reviewing the following materials, long term care facilities should consider the existence and adequacy of their current procedures regarding all treatment decisions. They should seek not only to develop, refine and improve existing procedures, but also to aid in increasing public awareness of issues involved in health care decisionmaking. By giving thoughtful attention to their own policies and procedures and the need for public directives, long term care providers can do much to facilitate medically and ethically appropriate decisionmaking for all individuals.

C. Categories of Decisions

For purposes of this discussion, treatment decisions can be divided into three categories: routine, non-routine and "life and death." While the same basic principles are applicable to all three, categorization is useful both for discussion purposes and to ensure adequate protection of all those involved in and affected by the decisionmaking process. Routine decisions, including those regarding most medications and non-invasive procedures, present few problems. Most long term care facility residents anticipate and accept as a matter of course routine and necessary treatment such as dressing changes, mild analgesics, or medication to regulate heart rate.

Non-routine decisions concern invasive procedures, such as any surgical procedure and administration of medications that have the potential for major effects on physical and mental conditions. These require that facilities observe additional procedures in terms of obtaining specific consent.

Treatment decisions with "life and death" implications have significant short-range effects on life expectancy; they are often the most difficult for residents and facilities alike. This can be due to the nature of the treatment, the uncertainty of its effects, or other factors in the resident's condition. For example, when an individual is suffering from a terminal disease, radical treatment for another illness may not be desirable or appropriate, even though not treating may result in an earlier death.

II. Legal Issues

The following sections provide an overview of the legal considerations involved in health care decisionmaking and the specific issues confronted by providers in individual cases. Again, state law will generally determine procedural decisionmaking requirements for each jurisdiction.

A. Informed Consent

The doctrine of informed consent speaks to an ideal of how medical decisionmaking between patient and physician should be conducted. On the one hand, the physician can bring to bear expertise in explaining a particular diagnosis or type of treatment. The patient on the other hand, knows his or her goals, values, and ability to endure treatment. Through a collaborative process, these two types of expertise can be combined, resulting, ideally, in the best decision for a particular patient. The legal doctrine of informed consent, seeking to encourage individual autonomy and rational decisionmaking, requires full disclosure of information to patients, and the obtaining of patients' permission prior to specific procedures being performed.

In general, a competent person has the right to refuse medical treatment in appropriate circumstances,

determined by balancing the individual's interests in self-determination against countervailing state interests, particularly the state's interest in preserving life. Other state interests include the protection of third parties who may be dependent on the individual refusing treatment, the prevention of suicide, and the preservation of ethical integrity of the medical profession. The right to refuse life-sustaining treatment generally follows the precepts of the informed consent doctrine.

B. Competency

An individual must be presumed competent and able to make informed decisions unless he or she is determined, according to applicable law, to be incompetent. Incompetence comprises an established exception to the informed consent doctrine. Unfortunately, little judicial guidance exists to define incompetency or to establish applicable standards. Additionally, doctrines regarding incompetency and guardianship often make no provision for the individual who is questionably competent or exhibits intermittent or limited decisionmaking impairment. For purposes of this discussion, competency or decisionmaking capacity can be defined in terms of an individual's capability to understand information relevant to the medical decision at hand, and to reason about relevant alternatives against a background of stable personal values and life goals. (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making Health Care Decisions*. Washington, D.C.: 1981.)

An advance directive is an oral or written instruction prepared by an individual concerning his or her health care in the event of later loss of competence or decisionmaking capacity. Some states have enacted statutes prescribing standards applicable to advance directives. "Living wills," for example, are a type of advance directive, as are durable powers of attorney which name persons with authority to make medical decisions on another's behalf. State law will determine the validity of a particular advance directive in each case. In states in which living wills or similar documents are legislatively authorized or judicially considered as valid, the wishes of the individual, as stated in these documents, will generally be honored, even if the individual is incompetent at the time the treatment decision must be made.

C. Surrogates

For individuals who are unable to be responsible for making their own decisions and who have not previously expressed their wishes by legally acceptable means, a surrogate decisionmaking process is required. A surrogate decisionmaker, for purposes of this discussion, is anyone who has the legal authority to make health care decisions for another, such as the court-appointed guardian of an individual who has been declared incompetent or the attorney-in-fact named in a durable power of attorney. Using the categorization of treatment decisions referenced previously, a guardian generally may make "routine" and "non-routine" medical decisions independently. An attorney-in-fact may make decisions specifically authorized or permitted by law. For "life and death" and other specified treatment decisions, special procedures or specific authority typically are required, although several states permit designation of a surrogate to make all such decisions.

Often, long term care facilities must address the question of decisionmaking for a questionably competent (or apparently incompetent) resident who has not executed a durable power of attorney and for whom a guardian has not been appointed. Unless state law specifically permits decisionmaking, under these circumstances, by a family member or other individual, facilities often have no alternative other than to seek judicial direction when particularly invasive "non-routine" or "life and death" decisions must be made, while depending upon an informal process, involving family or friends, for "routine" or some non-invasive "non-routine" decisions.

When a durable power of attorney has been executed, the question often arises as to when the individual has become sufficiently incapable of making decisions so as to require the attorney-in-fact to exercise his authority. Often the person is not sufficiently impaired to be legally incompetent, and the impairment itself may be intermittent or selective so that decisionmaking ability varies from time to time or situation to situation. If the individual is included in the decisionmaking process and if his or her expressed wishes and the decision of the attorney-in-fact are compatible, no problems should arise. If, however, there is disagreement, the differences must be reconciled before a valid decision can be made. In this case, judicial resolution may be required.

Judicial proceedings may also be necessary when any interested person questions the decision of the surrogate or when a decision must be made which is beyond the scope of the surrogate's authority. In some jurisdictions, an institutional ethics or oversight committee may reconcile differences and make or approve treatment decisions. In any type of surrogate decisionmaking, the wishes of the individual should be ascertained whenever possible and, when known, should be given great weight. In general, the more significant the decision, the greater the need

for understanding and agreement among those involved in and affected by it.

III. Developing Policies and Procedures

A. The Policy Development Process

As noted, facilities must address, in both the long and short-term, development of policies and procedures which ensure legally, medically and ethically sound decisionmaking. Long term resolution will generally require state legislative action. In order to achieve passage of appropriate laws, legislators, special interest groups, and the public must be informed of issues and given opportunity to discuss them and otherwise participate in the legislative development process. Because health care providers are knowledgeable about the broad spectrum of these issues, they should participate actively in the information dissemination, discussion and legislative development processes.

While meeting their long-range responsibility, providers can and should develop policies and procedures for present use. These must conform with existing state law, protect residents for whom decisions must be made, and be satisfactory to families, staff and others interested in and affected by those decisions.

At the outset, facilities should consider involving individuals from outside the facility in the policy development process. Valuable input may be obtained from representatives of the community, consumer advocacy organizations, the long term care ombudsman program, professional groups that provide services in the facility, residents and their families, clergy, attorneys, scholars and facility staff. Facilities should also be familiar with the policies and procedures of other institutional health care providers in their communities and states. Goals should be clearly defined so that all involved in the process understand and accept them. Those involved should be assigned responsibilities for writing, consulting and reviewing the policies as they are developed. Particular attention should be paid to ensuring that those individuals who will be affected by the policies and procedures are able to provide comments. Facility policy should also address the need for initial and continued staff education at all levels. Finally, provision should be made for review, by legal counsel experienced in health care issues, of any policy prior to its adoption and implementation.

B. Interests to be Considered

Before developing specific procedures to be followed, the drafters of facility policies must consider the framework within which health care decisions affecting residents will be made and the interests of the respective parties involved in any given decision: the resident, the facility, the resident's family and society as a whole. Legal concerns must also be addressed.

The interests of the individual most affected by health care decisions—the resident—must be considered first. Residents' rights, as defined by state and federal law and regulations, include the right to appropriate treatment, to be fully informed of and participate in decisions involving treatment, and to have one's dignity and wishes respected. The constitutional right to privacy includes the right to control one's own body, with decisions based upon the individual's beliefs, values and desires.

Health care providers—facility owners, administrators and staff, physicians and other involved professionals—also have interests that must be considered in drafting facility decisionmaking policies. These interests include personal values and beliefs, professional codes of ethics, applicable laws, the allocation of health care resources, the commitment to provide care and concerns about insurance coverage and legal liability.

Also to be considered in the drafting process are family concerns, including the welfare of loved ones, the family's relationship with the resident and personal values.

As noted previously, society as a whole has an interest in cumulative and long-range implications of medical decisions, their financial and ethical costs, equitable resource allocation and the decisionmaking processes used.

Finally, legal concerns accompanying any medical decisions include the existence of applicable and appropriate law and its orderly, consistent interpretation and application. Identification of applicable criteria and acceptable procedures are essential components of such laws.

C. Specific Issues to be Addressed

Policies should identify those responsible for initiating and implementing decisionmaking procedures, methods for designating surrogates and rendering decisions, and the events (such as change in resident condition) that require initiation of any formalized review process. The following issues should be considered.

1. *Specific decision categories:* Procedures should be developed for each category of medical decision to be made in the long term care facility, including identification of medical and other staff involved, procedures to be followed if disagreement exists, and documentation required in each case. Again, it

should be emphasized that, in each category, the competent resident's decision generally will control and that the wishes of the questionably competent or judicially declared incompetent resident should, whenever possible, be ascertained and given great weight in the decisionmaking process.

a. *Routine treatment decisions:* Procedures for routine treatment decisions need not be unnecessarily involved or prolonged. Often, a general consent signed at the time of admission will be sufficient authority for the provision of simple treatments and medications. Facilities should, however, make every effort to ensure that even the simplest treatments and medications are not initiated, modified or terminated without informing residents or, if necessary, families and surrogates and giving them opportunity to consent or object to the proposed treatment or medication. Often the charge nurse, after consulting with the physician, can perform this task.

b. *Non-routine treatment decisions:* For decisions other than routine decisions, the physician should be responsible for obtaining specific consent. In some cases, a notation on the chart will be sufficient documentation. In others, depending upon state law, written consent must be obtained from the competent resident or, for an incompetent or questionably competent resident, from the surrogate decisionmaker.

c. *"Life and death" treatment decisions:* For life and death treatment decisions, precise and thorough procedures addressing the issues described below should be established.

i. *Disclosure and consent:* Facility procedures should assign one individual primary responsibility for providing information to the resident and/or the surrogate decisionmaker and eliciting their opinions. Generally, this person should be the attending physician, although nursing staff may provide reinforcement and support to the resident and family.

ii. *Decisions to withhold treatment:* Facility procedures should identify specific criteria, such as patient condition or prognosis, that must be considered in making decisions not to treat or to cease treatment. For example, a policy might require, as a prerequisite to withholding treatment, that the physician make a specific determination that a resident is terminally ill or in a medically hopeless condition, that little improvement or benefit can be expected from the treatment being considered and/or that the benefit of a given treatment is outweighed by the burdens it would impose.

iii. *Evaluation criteria:* Facility procedures should set forth criteria for evaluating the relative benefits and burdens of the treatment being considered. For example, surgery that is not expected to prolong life may be appropriate if it will relieve pain significantly. Conversely, it may be inappropriate to initiate or continue a treatment that can only extend for a short period of time the life of an individual who is in great pain, if the pain cannot be relieved.

iv. *Review of prior decisions:* Facility procedures should address circumstances and time frames for review of decisions to withhold treatment or initiate treatment, including a provision for periodic review and reevaluation. Marked change in a resident's mental or physical condition will require review of previous decisions. Even when an individual has executed an advance directive, periodic review should take place to ascertain that the individual's wishes have not changed.

v. *Documentation:* Facility procedures should set forth the amount and kind of documentation to be required in specific instances of life and death decisionmaking. At minimum, the record should document discussions with the resident, family and any surrogate decisionmaker; the participants in and results of team conferences; the resident's continuing physical and mental condition; and the evaluation of treatments being considered.

2. *Decisionmakers:* Facility procedures should identify the categories of individuals who may appropriately be involved in the decisionmaking process, including the attending physician, surrogate decisionmaker, the resident's clergyman or a long term care ombudsman representative. The attending physician has responsibility for informing residents and their families about treatment choices. If a team or committee will be utilized, procedures should

specify the composition, scope, responsibility and authority of the committee in conformance with state law. The process must be flexible enough to permit decisionmaking in varied situations. Facility staff should not be responsible for informing residents and their families of treatment choices or for participating in the actual decision. They may, however, upon request, present information in response to the concerns of those having responsibility.

D. Implementing the Decisionmaking Procedures

Incident to admission, the resident, family or guardian should be informed of the facility's policy and procedures. The policy may provide for the dissemination of information regarding durable powers of attorney and, if state law permits, the execution and application of living wills and similar documents. Although the facility should neither encourage nor be actively involved in execution of these documents, copies should be obtained and placed in the medical record. Often, when state law does not specifically provide for living wills, courts will give great deference to the wishes of the individual expressed in such a document—clearly a benefit to the facility faced with difficult decisions concerning an incompetent or questionably competent resident. Documentation of expressed wishes of the resident, family or guardian should also be included in the medical record. Additionally, the medical record should contain sufficient information so that the procedures to be followed are current and clear.

Overall, facility policies concerning medical decisionmaking generally, and "life and death" decisionmaking in particular, should be clear, explicit and consistently applied.

While the professionals involved in the actual decisionmaking process may understand the reasoning involved, many staff members will need special help in understanding why and how these decisions are made. Facility policies should be flexible enough to account for individual circumstances and staff should be given sufficient information to understand the differences.

Direct care staff, in particular, will need careful training and continued support to carry out "comfort measures only" or supportive care plans. Physicians' orders that include detailed components of a supportive care plan for the individual resident should be required by the facility's procedures.

Under no circumstances should it be possible to infer that the resident for whom supportive care only is appropriate has been abandoned by the health care team or the facility.

Conclusion

In summary, changing medical technology and increased capacity to prolong life are presenting health care providers with new responsibilities and opportunities. Providers will have the opportunity to participate in shaping public policy and law concerning health care decisionmaking. However, they are well advised to first fulfill their responsibilities to develop appropriate procedures to aid in prompt, orderly and informed decisionmaking within their own facilities. Only by striving to develop and follow legally, medically and ethically sound practices will providers be able to adapt to continued changes, and provide the best possible care for their residents.

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APPENDIX J

POLICY AND STATEMENT

The Patient's Choice of Treatment Options

Policy

Health care decision making should be based on a collaborative relationship between the patient and the physician and/or other health care professionals who are primarily responsible for the patient's care.* The collaborative framework encourages communication, which contributes to sound decision making. Whenever possible, however, the authority to determine the course of treatment, if any, should rest with the patient, who may choose to delegate it. In the hospital setting, institutional methods should be established to reasonably assure that the patient may exercise this authority on the basis of relevant information necessary to make a sufficiently voluntary and informed decision. In addition, the health care institution should have methods to identify circumstances under which the patient's authority may be constrained, and recourse to the judgment of others, including the courts, is appropriate.

Statement

The right and responsibility to select among treatment options** presumes that the patient is capable of consulting with the physician about and understanding the available treatment alternatives and their implications and making a choice. Consultation might also take place with other responsible or authorized health care professionals involved in coordinating the patient's care. This process requires the patient's adequately-informed consent and may involve an evaluation of the patient's capacity to make a decision.

Collaborative Decision Making

Informed consent should reflect shared or collaborative decision making by the patient and the physician. The physician should provide information on the patient's condition, the recommended procedure and/or treatment with its significant benefits and risks, the significant alternatives for care or treatment (including no specific treatment), and the likely duration of incapacitation, if any.† Because patient's understanding of this information is essential to informed consent, care should be taken to present it in language familiar to them. Although institutional policy should promote documentation of consent decisions, such documentation is evidence of but not a substitute for communication and understanding between patient and physician. Unless the physician believes the patient would object, it may be advisable and useful if this information is shared with the patient's family, which often is a valuable resource for both the patient and the physician. Health care institutions and professionals should see to it that patients have access to understandable information relevant to the treatment choices before them.

In cases where the patient has chosen to delegate the treatment choice selection to the physician or someone else, a discussion with the patient about the implications and ramifications of the treatment course to be pursued is still recommended. Often family and friends should be included in this discussion.

In some emergencies, obtaining voluntary and adequately informed consent may not be possible or may be detrimental to the patient's well-being. In such cases, the patient's consent to the course of treatment chosen by a physician may be legally implied from the urgent circumstances surrounding the provision of that care.

*The term **physician** is used throughout the document, although other health care professionals may be responsible for or authorized to provide patient care.

**For the purpose of this document, treatment can be interpreted to include diagnostic as well as therapeutic procedures.

†See the AHA *Policy on A Patient's Bill of Rights*.

This policy and statement was developed by the Special Committee on Biomedical Ethics, which had been established by the General Council in January 1985 to consider various aspects of biomedical ethical issues facing the health care field.

This document replaces the *Guidelines on the Right of the Patient to Refuse Treatment* that was approved in 1975. The House of Delegates approved the policy and statement in February 1985.

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Implications of Treatment Choice

The right to choose treatment includes the right to refuse a specific treatment or all treatment, or select an alternative form of treatment. If the patient decides to refuse all treatment, a written informed refusal is strongly recommended to protect the hospital, the physicians, and all other personnel from liability, if any, for failure to furnish treatment. This decision should also be documented on the patient's chart.

If a patient chooses a course of treatment that is not acceptable to the attending physicians or other health care professionals, those individuals may withdraw from the case, so long as doing so does not amount to legal abandonment. If a suitably qualified alternative physician or health care professional willing to comply with the patient's preference is available, transfer to the care of that individual should be offered to the patient. If no physician or qualified health care professional is willing to undertake the patient's choice of treatment, the hospital should have a policy to address what procedures relative to care of the patient should be followed. The hospital also should have a policy to help identify and address those situations when the course of treatment selected is unacceptable to the mission of the institution.

Laws regarding the right of a patient or someone on the patient's behalf to refuse treatment vary from state to state. Some state laws limit a patient's right to refuse treatment, and others make provisions to facilitate the exercise of this right. The hospital's and the physician's response to a refusal, whether action or nonaction, must be consistent with applicable law. If a refusal can potentially result in substantial detriment to the patient's health and well-being, institutions should require that the appropriate administrative authority be informed. Protection of the patient's authority to select treatment at times may require either legal counsel or judicial proceedings.

Decision-Making Capacity

Decision-making capacity is the ability to make choices that reflect an understanding and appreciation of the nature and consequences of one's actions. Attention should be paid to the difference between decision-making capacity and legal competency. Decision-making capacity may exist, as in the case of a minor, where no legal competency exists. Legal competency may exist where decision-making capacity does not, as in the case of a temporarily impaired adult who has not been deemed legally incompetent. In health care treatment decisions, decision-making capacity is best understood as the patient's ability to understand the nature and effects of treatment options, and appreciate the impact of a choice. Only when the patient's capacity to make decisions is definitely impaired and the effect of flawed decision making is potentially serious should the patient's right and responsibility for decision making be transferred to others.

When there is reason to doubt the usual presumption of adequate decision-making capacity, an assessment of capacity is made by the physician in consultation with the family, friends, nurses, and other health care professionals. The institution should have effective policies to facilitate assessment of patients' decision-making capacity. The institution should have methods to ensure that the physician conducts these assessments when necessary. The hospital should also see to it that there are accessible and practical avenues by which concerns about a patient's capacity to make decisions may be raised by others, including family, friends, nurses, and other health care professionals. The hospital may also wish to have a policy under which a patient, in appropriate circumstances, should be informed both of any concerns raised by the assessment and of access to procedures for reassessment or to legal counsel. Only when the determination regarding decision-making capacity is controversial among concerned persons (including the patient) should legal guardianship proceedings be required.

When a patient lacks adequate decision-making capacity, substantial effort should be made to ensure that the choice of medical treatment is consistent with the known views of patient. The decision makers must seek and take note of any information reflected in oral statements, life-style commitments, living wills, and so forth made by the patient before deterioration of decision-making capacity. These known views can sometimes be supplied by the family or an individual acting as surrogate. The surrogate should be a person or group of persons most likely to be able to advocate on the patient's behalf and to assess the patient's preferences and experiences. If the physician knows through informal communications, durable power of attorney, or living will of the patient's designation of a surrogate, that person should serve unless mitigating factors are apparent.

If the selection of the surrogate seems controversial, methods for institutional review and, if necessary, court adjudication are required. In some cases, court appointment of a surrogate may be legally required. The institution should be prepared to refer difficult cases to court for guardianship determinations.

Role of Minors in Decision Making

Patients who are minors should be allowed to participate in decision-making about their care to the extent possible with regard to their capacity to understand treatment options and outcomes.

When a minor is deemed legally incapable of making a decision, that is, not considered to be a "mature" or "emancipated" minor according to state law, the parent or legal guardian usually will have the final decision-making authority. Mature or emancipated minors, as determined by state law, should be treated as adults with decision-making capacity.

Institutions should establish policies concerning the circumstances under which legal advice is to be sought for either the institution or the minor, including cases where a parent or guardian makes a decision that may be deemed adverse to the interests of a minor or opposed to the expressed views of a relatively mature minor.

Management Practices and Procedures

Hospitals have a responsibility to assess the effect of management practices and procedures on patient decision-making options and to foster awareness among health care professionals and key hospital personnel that some institutional practices necessary to ensure efficiency, such as some admissions or food service procedures, can unintentionally limit patient choices. For example, the patient often does not have the opportunity to make many of the routine choices in day-to-day living—when to have meals, wake up, have visitors, etc.

Documentation of Decision Making

Documentation of decisions regarding patient treatment promotes orderly procedures and more thorough consideration of options. Documentation also provides legal protection for and is often in the best interests of patients, patients' families, concerned health professionals, and hospitals.

Conclusion

The patients' role in determining the course of their medical treatment must be ensured in the institutional setting. Although these decisions should be made in collaboration with the attending physicians, the hospital must take a leadership role in ensuring institutional practices that support patients' decision making and in identifying when recourse to the judgment of others is necessary.

APPENDIX K

UNIFORM ANATOMICAL GIFT ACT

An Act authorizing the gift of all or part of a human body after death for specified purposes.

1968 ACT

Sec.

1. Definitions.
2. Persons Who May Execute an Anatomical Gift.
3. Persons Who May Become Donees; Purposes for Which Anatomical Gifts May be Made.
4. Manner of Executing Anatomical Gifts.
5. Delivery of Document of Gift.
6. Amendment or Revocation of the Gift.
7. Rights and Duties at Death.
8. Uniformity of Interpretation.
9. Short Title.
10. Repeal.
11. Time of Taking Effect.

Be it enacted .....

§ 1. [Definitions]

(a) "Bank or storage facility" means a facility licensed, accredited, or approved under the laws of any state for storage of human bodies or parts thereof.

(b) "Decedent" means a deceased individual and includes a stillborn infant or fetus.

(c) "Donor" means an individual who makes a gift of all or part of his body.

(d) "Hospital" means a hospital licensed, accredited, or approved under the laws of any state; includes a hospital operated by the United States government, a state, or a subdivision thereof, although not required to be licensed under state laws.

(e) "Part" means organs, tissues, eyes, bones, arteries, blood, other fluids and any other portions of a human body.

(f) "Person" means an individual, corporation, government or governmental subdivision or agency, business trust, estate, trust, partnership or association, or any other legal entity.

(g) "Physician" or "surgeon" means a physician or surgeon licensed or authorized to practice under the laws of any state.

(h) "State" includes any state, district, commonwealth, territory, insular possession, and any other area subject to the legislative authority of the United States of America.

Source: National Conference Of Commissioners On Uniform State Laws.

§ 2. [Persons Who May Execute an Anatomical Gift.]

(a) Any individual of sound mind and 18 years of age or more may give all or any part of his body for any purpose specified in section 3, the gift to take effect upon death.

(b) Any of the following persons, in order of priority stated, when persons in prior classes are not available at the time of death, and in the absence of actual notice of contrary indications by the decedent or actual notice of opposition by a member of the same or a prior class, may give all or any part of the decedent's body for any purpose specified in section 3:

(1) the spouse,
(2) an adult son or daughter,
(3) either parent,
(4) an adult brother or sister,
(5) a guardian of the person of the decedent at the time of his death,
(6) any other person authorized or under obligation to dispose of the body.

(c) If the donee has actual notice of contrary indications by the decedent or that a gift by a member of a class is opposed by a member of the same or a prior class, the donee shall not accept the gift. The persons authorized by subsection (b) may make the gift after or immediately before death.

(d) A gift of all or part of a body authorizes any examination necessary to assure medical acceptability of the gift for the purposes intended.

(e) The rights of the donee created by the gift are paramount to the rights of others except as provided by Section 7(d).

§ 3. [Persons Who May Become Donees; Purposes for Which Anatomical Gifts May be Made]

The following persons may become donees of gifts of bodies or parts thereof for the purposes stated:

(1) any hospital, surgeon, or physician, for medical or dental education, research, advancement of medical or dental science, therapy, or transplantation; or

(2) any accredited medical or dental school, college or university for education, research, advancement of medical or dental science, or therapy; or

(3) any bank or storage facility, for medical or dental education, research, advancement of medical or dental science, therapy, or transplantation; or

(4) any specified individual for therapy or transplantation needed by him.

§ 4. [Manner of Executing Anatomical Gifts]

(a) A gift of all or part of the body under Section 2(a) may be made by will. The gift becomes effective upon the death of the testator without waiting for probate. If the will is not probated, or if it is declared invalid for testamentary purposes, the gift, to the extent that it has been acted upon in good faith, is nevertheless valid and effective.

(b) A gift of all or part of the body under Section 2(a) may also be made by document other than a will. The gift becomes effective upon the death of the donor. The document, which may be a card designed to be carried on the person, must be signed by the donor [in the presence of 2 witnesses who must sign the document in his presence]. If the donor cannot sign, the document may be signed for him at his direction and in his presence in the presence of 2 witnesses who must sign the document in his presence. Delivery of the document of gift during the donor's lifetime is not necessary to make the gift valid.

(c) The gift may be made to a specified donee or without specifying a donee. If the latter, the gift may be accepted by the attending physician as donee upon or following death. If the gift is made to a specified donee who is not available at the time and place of death, the attending physician upon or following death, in the absence of any expressed indication that the donor desired otherwise, may accept the gift as donee. The physician who becomes a donee under this subsection shall not participate in the procedures for removing or transplanting a part.

(d) Notwithstanding Section 7(b), the donor may designate in his will, card, or other document of gift the surgeon or physician to carry out the appropriate procedures. In the absence of a designation or if the designee is not available, the donee or other person authorized to accept the gift may employ or authorize any surgeon or physician for the purpose.

(e) Any gift by a person designated in Section 2(b) shall be made by a document signed by him or made by his telegraphic, recorded telephonic, or other recorded message.

Anatomical Gift by a Living Donor

I am of sound mind and 18 years or more of age. I hereby make this anatomical gift to take effect upon my death. The marks in the appropriate squares and words filled into the blanks below indicate my desires.

I give:

☐ my body;
☐ any needed organs or parts;
☐ the following organs or parts _____;

To the following person (or institution):

☐ physician in attendance at my death;
☐ the hospital in which I die;
☐ the following named physician, hospital, storage bank or other medical institution _____;
☐ the following individual for treatment _____;

for the following purposes:

☐ any purpose authorized by law;
☐ transplantation;
☐ therapy;
☐ research;
☐ medical education.

Dated _____ City and State _____

Signed by the Donor in the presence of the following who sign as witnesses:

_____
Signature of Donor

_____
Address of Donor

_____
Witness

_____
Witness

Anatomical Gift by Next of Kin or Other Authorized Person

I hereby make this anatomical gift of or from the body of _____ who died on _____ at the _____ in _____. The marks in the appropriate squares and the words filled into the blanks below indicate my relationship to the deceased and my desires respecting the gift.

I am the surviving:

☐ spouse;
☐ adult son or daughter;
☐ parent;
☐ adult brother or sister;
☐ guardian;
☐ _____, authorized to dispose of the body;

I give ☐ the body of deceased, ☐ any needed organs or parts, ☐ the following organs or parts

_____;

To the following person (or institution)

_____

(insert the name of a physician, hospital, research or educational institution, storage bank or individual),

for the following purposes

☐ any purpose authorized by law;
☐ transplantation,
☐ therapy;
☐ research;
☐ medical education.

Dated _____ City and State _____

_____

Signature of Survivor

_____

Address of Survivor

§ 5. [Delivery of Document of Gift]

If the gift is made by the donor to a specified donee, the will, card, or other document, or an executed copy thereof, may be delivered to the donee to expedite the appropriate procedures immediately after death. Delivery is not necessary to the validity of the gift. The will, card, or other document, or an executed copy thereof, may be deposited in any hospital, bank or storage facility or registry office that accepts it for safekeeping or for facilitation of procedures after death. On request of any interested party upon or after the donor's death, the person in possession shall produce the document for examination.

§ 6. [Amendment or Revocation of the Gift]

(a) If the will, card, or other document or executed copy thereof, has been delivered to a specified donee, the donor may amend or revoke the gift by:

(1) the execution and delivery to the donee of a signed statement, or
(2) an oral statement made in the presence of 2 persons and communicated to the donee, or
(3) a statement during a terminal illness or injury addressed to an attending physician and communicated to the donee, or
(4) a signed card or document found on his person or in his effects.

(b) Any document of gift which has not been delivered to the donee may be revoked by the donor in the manner set out in subsection (a), or by destruction, cancellation, or mutilation of the document and all executed copies thereof.

(c) Any gift made by a will may also be amended or revoked in the manner provided for amendment or revocation of wills, or as provided in subsection (a).

§ 7. [Rights and Duties at Death]

(a) The donee may accept or reject the gift. If the donee accepts a gift of the entire body, he may, subject to the terms of the gift, authorize embalming and the use of the body in funeral services. If the gift is of a part of the body, the donee, upon the death of the donor and prior to embalming, shall cause the part to be removed without unnecessary mutilation. After removal of the part, custody of the remainder of the body vests in the surviving spouse, next of kin, or other persons under obligation to dispose of the body.

(b) The time of death shall be determined by a physician who tends the donor at his death, or, if none, the physician who certifies the death. The physician shall not participate in the procedures for removing or transplanting a part.

(c) A person who acts in good faith in accord with the terms of this Act or with the anatomical gift laws of another state [or a foreign country] is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act.

(d) The provisions of this Act are subject to the laws of this state prescribing powers and duties with respect to autopsies.

§8. [Uniformity of Interpretation]

This Act shall be so construed as to effectuate its general purpose to make uniform the law of those states which enact it.

§ 9. [Short Title]

This Act may be cited as the Uniform Anatomical Gift Act.

§10. [Repeal]

The following acts and parts of acts are repealed:

(1)
(2)
(3)

§11. [Time of Taking Effect]

This Act shall take effect .....

APPENDIX L

GUIDELINES FOR THE DETERMINATION OF DEATH

Report of the Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

The guidelines set forth in this report represent the views of the signatories as individuals, they do not necessarily reflect the policy of any institution or professional association with which any signatory is affiliated. Although the practice of individual signatories may vary slightly, signatories agree on the acceptability of these guidelines: Jesse Barber, MD; Don Becker, MD; Richard Behrman, MD, JD; Donald R. Bennett, MD; Richard Bereaford, MD, JD; Reginald Bickford, MD; William A. Black, Jr., MD; Benjamin Boshes, MD, PhD; Philip Bravnstein, MD; John Burroughs, MD, JD; Russell Butler, MD; John Caronna, MD; Shelley Chou, MD, PhD; Kemp Clark, MD; Ronald Cranford, MD; Michael Earnest, MD; Albert Ehle, MD; Jack M. Fein, MD; Sal Fiscina, MD, JD; Terrance G. Furlow, MD, JD; Eli Goldensohn, MD; Jack Grabow, MD; Phillip M. Green, MD; Ake Grenvik, MD; Charles E. Henry, PhD; John Hughes, MD, PhD, DM; Howard Kaufman, MD; Robert King, MD; Julius Korein, MD; Thomas W. Langfitt, MD; Cesare Lombroso, MD; Kevin M. McIntyre, MD, JD; Richard L. Masland, DM; Don Harper Mills, MD, JD; Gaetano Molinari, MD; Byron C. Pevehouse, MD; Lawrence H. Pitts, MD; A. Bernard Pleet, MD; Fred Plum, MD; Jerome Posner, MD; David Powner, MD; Richard Rovit, MD; Peter Safar, MD; Henry Schwartz, MD; Edward Schlesinger, MD; Roy Selby, MD; James Snyder, MD; Bruce F. Sorenson, MD; Cary Sufer, MD; Barry Tharp, MD; Fernando Torres, MD; A. Earl Walker, MD; Arthur Ward, MD; Jack Whisnant, MD; Robert Wilkus, MD; and Harry Zimmerman, MD.

The preparation of this report was facilitated by the President's Commission but the guidelines have not been passed on by the Commission and are not intended as matters for governmental review or adoption.

The advent of effective artificial cardiopulmonary support for severely brain-injured persons has created some confusion during the past several decades about the determination of death. Previously, loss of heart and lung functions was an easily observable and sufficient basis for diagnosing death, whether the initial failure occurred in the brain, the heart and lungs, or elsewhere in the body. Irreversible failure of either the heart and lungs or the brain precluded the continued functioning of the other. Now, however, circulation and respiration can be maintained by means of a mechanical respirator and other medical interventions, despite a loss of all brain functions. In these circumstances, we recognize as dead an individual whose loss of brain functions is complete and irreversible.

To recognize reliably that death has occurred, accurate criteria must be available for physicians' use. These now fall into two groups, to be applied depending on the clinical situation. When respiration and circulation have irreversibly ceased, there is no need to assess brain functions directly. When cardiopulmonary functions are artificially maintained, neurological criteria must be used to assess whether brain functions have ceased irreversibly.

More than half of the states now recognize, through statutes or judicial decisions, that death may be determined on the basis of irreversible cessation of all functions of the brain. Law in the remaining states has not yet departed from the older, common-law view that death has not occurred until "all vital functions" (whether or not artificially maintained) have ceased. The language of the statutes has not been uniform from state to state, and the diversity of proposed and enacted laws has created substantial confusion. Consequently, the American Bar Association, the American Medical Association, the National Conference of Commissioners on Uniform State Laws, and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research have proposed the following model statute, intended for adoption in every jurisdiction:

Source: Report by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Defining Death," U.S. Government Printing Office (1981), pages 159–166.

UNIFORM DETERMINATION OF DEATH ACT

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

This wording has also been endorsed by the American Academy of Neurology and the American Electroencephalographic Society.

The statute relies on the existence of "accepted medical standards" for determining that death has occurred. The medical profession, based on carefully conducted research and extensive clinical experience, has found that death can be determined reliably by either cardiopulmonary or neurological criteria. The tests used for determining cessation of brain functions have changed and will continue to do so with the advent of new research and technologies. The "Harvard criteria" (*JAMA* 1968; 205:337–340) are widely accepted, but advances in recent years have led to the proposal of other criteria. As an aid to the implementation of the proposed uniform statute, we provide here one statement of currently accepted medical standards.

INTRODUCTION

The criteria that physicians use in determining that death has occurred should (1) eliminate errors in classifying a living individual as dead; (2) allow as few errors as possible in classifying a dead body as alive; (3) allow a determination to be made without unreasonable delay; (4) be adaptable to a variety of clinical situations; and (5) be explicit and accessible to verification.

Because it would be undesirable for any guidelines to be mandated by legislation or regulation or to be inflexibly established in case law, the proposed Uniform Determination of Death Act appropriately specifies only "accepted medical standards." Local, state, and national institutions and professional organizations are encouraged to examine and publish their practices.

The following guidelines represent a distillation of current practice in regard to the determination of death. Only the most commonly available and verified tests have been included. The time of death recorded on a death certificate is at present a matter of local practice and is not covered in this document.

These guidelines are advisory. Their successful use requires a competent and judicious physician, experienced in clinical examination and the relevant procedures. All periods of observation listed in these guidelines require the patient to be under the care of a physician. Considering the responsibility entailed in the determination of death, consultation is recommended when appropriate.

The outline of the criteria is set forth below in boldface letters. The lightface text that follows each heading explains its meaning. In addition, the two sets of criteria (cardiopulmonary and neurological) are followed by a presentation of the major complicating conditions: drug and metabolic intoxication, hypothermia, young age, and shock. It is of paramount importance that anyone referring to these guidelines be thoroughly familiar with the entire document, including explanatory notes and complicating conditions.

THE CRITERIA FOR DETERMINATION OF DEATH

An individual presenting the findings in *either* section A (cardiopulmonary) *or* section B (neurological) is dead. In either section, a diagnosis of death requires that ***both cessation of functions***, as set forth in subsection 1, ***and irreversibility***, as set forth in subsection 2, be demonstrated.

A. An individual with irreversible cessation of circulatory and respiratory functions is dead.

1. *Cessation* is recognized by an appropriate clinical examination.

Clinical examination will disclose at least the absence of responsiveness, heartbeat, and respiratory effort. Medical circumstances may require the use of confirmatory tests, such as an ECG.

2. *Irreversibility* is recognized by persistent cessation of functions during an appropriate period of observation and/or trial of therapy.

In clinical situations where death is expected, where the course has been gradual, and where irregular agonal respiration or heartbeat finally ceases, the period of observation following the cessation may be only the few minutes required to complete the examination. Similarly, if resuscitation is not undertaken and ventricular fibrillation and standstill develop in a monitored patient, the required period of observation thereafter may be as short as a few minutes. When a possible death is unobserved, unexpected, or sudden, the examination may need to be more detailed and repeated over a longer period, while appropriate resuscitative effort is maintained as a test of cardiovascular responsiveness. Diagnosis

in individuals who are first observed with rigor mortis or putrefaction may require only the observation period necessary to establish that fact.

B. An individual with irreversible cessation of all functions of the entire brain, including the brain stem, is dead. The "functions of the entire brain" that are relevant to the diagnosis are those that are clinically ascertainable. Where indicated, the clinical diagnosis is subject to confirmation by laboratory tests, as described in the following portions of the text. Consultation with a physician experienced in this diagnosis is advisable.

1. *Cessation* is recognized when evaluation discloses findings of a *and* b:

a. Cerebral functions are absent, and ...

There must be deep coma, that is, cerebral unreceptivity and unresponsivity. Medical circumstances may require the use of confirmatory studies such as an EEG or blood-flow study.

b. brain stem functions are absent.

Reliable testing of brain stem reflexes requires a perceptive and experienced physician using adequate stimuli. Pupillary light, corneal, oculocephalic, oculovestibular, oropharyngeal, and respiratory (apnea) reflexes should be tested. When these reflexes cannot be adequately assessed, confirmatory tests are recommended.

Adequate testing for apnea is very important. An accepted method is ventilation with pure oxygen or an oxygen and carbon dioxide mixture for ten minutes before withdrawal of the ventilator, followed by passive flow of oxygen. (This procedure allows $PaCO_2$ to rise without hazardous hypoxia.) Hypercarbia adequately stimulates respiratory effort within 30 seconds when $PaCO_2$ is greater than 60 mm Hg. A ten-minute period of apnea is usually sufficient to attain this level of hypercarbia. Testing of arterial blood gases can be used to confirm this level. Spontaneous breathing efforts indicate that part of the brain stem is functioning.

Peripheral nervous system activity and spinal cord reflexes may persist after death. True decerebrate or decorticate posturing or seizures are inconsistent with the diagnosis of death.

2. *Irreversibility* is recognized when evaluation discloses findings of a *and* b *and* c:

a. The cause of coma is established and is sufficient to account for the loss of brain functions, and ...

Most difficulties with the determination of death on the basis of neurological criteria have resulted from inadequate attention to this basic diagnostic prerequisite. In addition to a careful clinical examination and investigation of history, relevant knowledge of causation may be acquired by computed tomographic scan, measurement of core temperature, drug screening, EEG, angiography, or other procedures.

b. the possibility of recovery of any brain functions is excluded, and ...

The most important reversible conditions are sedation, hypothermia, neuromuscular blockade, and shock. In the unusual circumstance where a sufficient cause cannot be established, irreversibility can be reliably inferred only after extensive evaluation for drug intoxication, extended observation, and other testing. A determination that blood flow to the brain is absent can be used to demonstrate a sufficient and irreversible condition.

c. the cessation of all brain functions persists for an appropriate period of observation and/or trial of therapy.

Even when coma is known to have started at an earlier time, the absence of all brain functions must be established by an experienced physician at the initiation of the observation period. The duration of observation periods is a matter of clinical judgment, and some physicians recommend shorter or longer periods than those given here.

Except for patients with drug intoxication, hypothermia, young age, or shock, medical centers with substantial experience in diagnosing death neurologically report no cases of brain functions returning following a six-hour cessation, documented by clinical examination and confirmatory EEG. In the absence of confirmatory tests, a period of observation of at least 12 hours is recommended when an irreversible condition is well established. For anoxic brain damage where the extent of damage is more difficult to ascertain, observation for 24 hours is generally desirable. In anoxic injury, the observation period may be reduced if a test shows cessation of cerebral blood flow or if an EEG shows electrocerebral silence in an adult patient without drug intoxication, hypothermia, or shock.

Confirmation of clinical findings by EEG is desirable when objective documentation is needed to substantiate the clinical findings. Electrocerebral silence verifies irreversible loss of cortical functions, except in patients with drug intoxication or hypothermia. (Important technical details are provided in "Minimal Technical Standards for EEG Recording in Suspected Cerebral Death" [*Guidelines in EEG 1980*. Atlanta, American Electroencephalographic Society, 1980, section 4, pp. 19–24].) When joined with the clinical findings of absent brain stem functions, electrocerebral silence confirms the diagnosis.

Complete cessation of circulation to the normothermic adult brain for more than ten minutes is incompatible with survival of brain tissue. Documentation of this circulatory failure is therefore evidence of death of the entire brain. Four-vessel intracranial angiography is definitive for diagnosing cessation of circulation to the entire brain (both cerebrum and posterior fossa) but entails substantial practical difficulties and risks. Tests are available that assess circulation only in the cerebral hemispheres, namely radioisotope bolus cerebral angiography and gamma camera imaging with radioisotope cerebral angiography. Without complicating conditions, absent cerebral blood flow as measured by these tests, in conjunction with the clinical determination of cessation of all brain functions for at least six hours, is diagnostic of death.

COMPLICATING CONDITIONS

A. Drug and Metabolic Intoxication.—Drug intoxication is the most serious problem in the determination of death, especially when multiple drugs are used. Cessation of brain functions caused by the sedative and anesthetic drugs, such as barbiturates, benzodiazepines, meprobamate, methaqualone, and trichloroethylene, may be completely reversible even though they produce clinical cessation of brain functions and electrocerebral silence. In cases where there is any likelihood of sedative presence, toxicology screening for all likely drugs is required. If exogenous intoxication is found, death may not be declared until the intoxicant is metabolized or intracranial circulation is tested and found to have ceased.

Total paralysis may cause unresponsiveness, areflexia, and apnea that closely simulates death. Exposure to drugs such as neuromuscular blocking agents or aminoglycoside antibiotics, and diseases like myasthenia gravis are usually apparent by careful review of the history. Prolonged paralysis after use of succinylcholine chloride and related drugs requires evaluation for pseudocholinesterase deficiency. If there is any question, low-dose atropine stimulation, electromyogram, peripheral nerve stimulation, EEG, tests of intracranial circulation, or extended observation, as indicated, will make the diagnosis clear.

In drug-induced coma, EEG activity may return or persist while the patient remains unresponsive, and therefore the EEG may be an important evaluation along with extended observation. If the EEG shows electrocerebral silence, short latency auditory or somatosensory-evoked potentials may be used to test brain stem functions, since these potentials are unlikely to be affected by drugs.

Some severe illnesses (eg, hepatic encephalopathy, hyperosmolar coma, and preterminal uremia) can cause deep coma. Before irreversible cessation of brain functions can be determined, metabolic abnormalities should be considered and, if possible, corrected. Confirmatory tests of circulation or EEG may be necessary.

B. Hypothermia.—Criteria for reliable recognition of death are not available in the presence of hypothermia (below 32.2°C core temperature). The variables of cerebral circulation in hypothermic patients are not sufficiently well studied to know whether tests of absent or diminished circulation are confirmatory. Hypothermia can mimic brain death by ordinary clinical criteria and can protect against neurological damage due to hypoxia. Further complications arise since hypothermia also usually precedes and follows death. If these complicating factors make it unclear whether an individual is alive, the only available measure to resolve the issue is to restore normothermia. Hypothermia is not a common cause of difficulty in the determination of death.

C. Children.—The brains of infants and young children have increased resistance to damage and may recover substantial functions even after exhibiting unresponsiveness on neurological examination for longer periods compared with adults. Physicians should be particularly cautious in applying neurological criteria to determine death in children younger than 5 years.

D. Shock.—Physicians should also be particularly cautious in applying neurological criteria to determine death in patients in shock because the reduction in cerebral circulation can render clinical examination and laboratory tests unreliable.